BIG RED FACTOR

2021—Issue 4

NATIONAL HEMOPHILIA FOUNDATION
CHAPTER OF EXCELLENCE
2018-2020

Inside this issue:

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

We had hoped 2021 would be a more 'normal' year, but it came with it's own sets of challenges. However, we were able to host in person programming again this year and it made all the difference. It was so wonderful to see you again, and we can't wait to see the rest of you when you feel comfortable.

We grew as a chapter this year, both with new staff but also with new programs, an expanded vision and new goals for 2022. We know this year was hard for a lot of people still and we are so grateful for you allowing us to serve the bleeding disorders community and for you showing up in person, virtually and every way in between.

Sarah started this summer and has been a wonderful addition to NENHF. She has really worked on ensuring our teen program will blossom and has big plans for 2022. Our adult men got two of their own programs this year and have expressed a desire for more. We listened to what programs you wanted to see next year and are working on adding them. We would LOVE your voice in this growth. We are always looking for people to serve on committees to help us grow. If you are interested in advocacy, programs and education, fundraising and events or governance, we can use your voice.

As I wrap up my 6th year serving this community, I want to thank you from the bottom of my heart for being such a wonderful and loving group who never leaves anyone behind. Thank you for allowing Sarah and I to program for you and advocate with you for everyone with a bleeding disorder. It is truly an honor.

We have no idea what 2022 has is store for us but I know we will make the best of it. Have a safe and healthy New Year.

Maureen Grace, Executive Director

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

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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Program Manager
Sarah Arrieta

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The material in this newsletter is provided for your general information only. The Nebraska Chapter does not give medical advice or engage in the practice of medicine. NHF-NE does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

2022
Events

Quarter 1 Events:
Virtual VWD Series
February

Advocacy Days
March 22-24th

(Quarter One events will be virtual with the hope of some in person Industry dinners)

Quarter 2 Events:
PING
April 9th (In-person)

NEW!!
Couple's Retreat
Tentatively April 24th

Adults with Bleeding Disorders
(Kearney, NE)
Saturday, May 21st

Family Camp (In person)
June 10-12th

Our goal is to offer as many programs in person as possible in 2022.
We will shift to virtual if needed.

combined health agencies drive
MEMBER CHARITY

2022 Calendar of Events

As of October 1, 2021- In order to attend an in person NENHF event you must show proof of vaccination or a negative Covid test within 72 hours of the event. This is for any attendee 12+. Children do not need a negative covid test but still will need a mask for indoor events.

January	February Virtual VWD Series- TBD	March Advocacy Days- 22-24th	April PING- 9th Couple's Retreat- 24th
May Adults with Bleeding Disorders (Kearney) 21st	June Family Camp 10-12th	July Infusion: Bloody Mary Mix Off 16th	August Family Ed Weekend (Lincoln) 6-7th
September Unite for Bleeding Disorders Walk 24th	October FAB Retreat 14-16th Harvest Fest 22nd	November Industry Symposium 5th	December Holiday PING 10th

These are tentative 2022 dates which are subject to change.
Other programs not included on this calendar:
Teen, Men's, Spanish, Dinners and other smaller events. Keep an eye on your email, Facebook and our website for updates.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

Washington Days

NHF's Washington Days is an opportunity for people affected by inherited blood disorders to advocate for issues that are important to them. In 2021, Washington Days had more than 400 volunteer advocates from 45 states that met with legislators and staff to discuss federal funding for bleeding disorder programs and support policies that increase affordability of coverage and access to care. The issues and priorities for 2022 Washington Days will be announced at the start of new year.

Please note that Washington Days 2022 will be an entirely virtual experience.

Washington Days programming will take place during the dates of March 1-2.

Learn More & Register

Preparatory webinars were hosted for the 2021 event.

Similar webinars are planned for February 15, 2022.

- Beginner advocates (0-1 times attending prior Washington Days): February 15, 2022, at 2:00-3:00 EST
- Advanced advocates (2 or more times attending Washington Days): February 15, 2022, at 3:30-4:00 EST

A final agenda for the 2022 events will be released closer to the conference. Below is a general outline for events:

Tuesday, March 1, 2022
Hill Visits and Issues Training - 3:00 p.m. – 5:00 p.m. EST
State Team Meetings – 5:00 p.m. – 5:30 p.m. EST

Wednesday, March 2, 2022
Hill visits - 9:00 a.m. – 5:00 p.m. EST

(exact schedules will be released by Sunday, February 28th, 2022)

Virtual Teen Cooking & Budgeting Class

The Virtual Teen Cooking & Budgeting Class was held on December 1rst. The teens were given the assignment of shopping for the best deals for their ingredients and keeping under their $40.00 budget. Although we started off the class with tZoom technical difficulties, we were able to discuss how to create a budget and different ways to shop for the best deals. We cooked chicken fajita quesadillas with a cilantro-lime crema with our favorite fabulous Chef Mike. We focused on our chopping skills when we cut up bell peppers, onions, and cilantro to name a few. This class helped us learn more about important life skills such as cooking and budgeting while having fun.

Looking into the future, we are working to develop dynamic and immersive activities for our teen community. We plan to have an educational dinner and escape room night coming up soon in 2022. We have asked our teen community what they would like to see for their programming, and we love to hear all their ideas. Sarah, our program manager, is planning to create more opportunities for leadership, advocacy, and self-efficacy in the future. Stay tuned for more opportunities and programs to come for our great group of teens.

Chronic Pain, CAM and YOU

Chronic Pain, CAM, and YOU

Laurie Kelley

Pain is highly personal. No two people experience the same feeling of pain, even when it's the same injury, like a muscle bleed, or experience, like childbirth. A joint bleed may feel tingling to one, stabbing to another, or throbbing to someone else. Mike Birmingham, a man with hemophilia A, writes in his blog *The Bleeding Edge*, "Pain is pretty deeply personal. I personally have never been able to figure out what to say when a nurse asks me to describe my pain."[1]

But it's especially personal when trying to describe the level of pain. Doctors often ask patients to rate their pain on a scale of 1 to 10. But what is a 1? What is a 10? A level 8 to one person might be a level 3 to another. Matt Rollins, who has hemophilia A, notes, "The HTC [hemophilia treatment center] will understand that most of us older guys have a base pain level that stays steady at a 5 or 6 every day. We've gotten used to that level of pain and this is our 'normal.' What's difficult is when you go to an ER and try to relay that same information." This is critical when people with bleeding disorders try to explain their level of pain to their doctor. Not appreciating or understanding how much pain a person is feeling may lead to an inefficient treatment for that pain.

Bonnie Charles interprets her pain at lower levels when compared to people without a bleeding disorder. "I feel like what would be painful to someone else is just the norm for me. And I don't find it painful because I've learned to live with it."

Because pain is so personal, medication may not be the first—or the only—option for chronic pain. Instead, both patient and physician can consider different types of *complementary and alternative medicine* (CAM) to learn how to handle chronic pain. And like pain, CAM can be highly personalized as well.

What Is CAM?

CAM is any *adjunct* (additional) therapy, like massage, used along with conventional medicine. It's an important part of a *multimodal* or multidisciplinary approach to pain management. It's also important in *integrative medicine*, which focuses on the whole person and makes use of all appropriate therapeutic approaches, healthcare professionals, and disciplines to achieve optimal health and healing. Here are some of the most common CAM therapies:

Relaxation Therapies. Relaxation teaches you to relieve tense muscles, reduce anxiety, and alter your mental state. Mindfulness meditation helps you focus attention on a specific object or your breathing patterns to induce relaxation. Guided imagery is a conscious meditation technique of relaxation followed by visualization of a soothing mental image, like walking on a beach at sunset. Barbara Forss, who has factor VII deficiency, recalls, "As a child, I developed a way to go to a 'lovely place' in my head during episodes of pain. I suppose it would be considered a form of guided imagery. While not taking the pain away, it helps me to manage it. As an adult, my lovely place is much the same as when I was a child. Just bigger...and with more animals!"

Biofeedback Training. You can learn how to recognize and change your biological reactions to stress and pain by using electronic equipment to monitor your physical responses: brain activity, blood pressure, muscle tension, and heart rate.

Chronic Pain Continued...

Behavior Modification. Some people with severe chronic pain may become anxious, depressed, homebound, dependent, or bedridden. Behavior modification helps you create a step-by-step approach to confronting challenges by changing your behavior and shifting your attitude. Matt Barkdull, a man with hemophilia B who is also a licensed mental health specialist, says, “Behavior modification and stress management are my go-to interventions. I resist the urge to curse my bad luck, attack my self-identity, or become bitter (for that which we harbor is that which we attract). I believe pain is there to teach me a lesson, to remind me to appreciate better days ahead. When I meditate upon these things, I become more grateful for the important things in my life, and make better decisions. These interventions seem to work best when pain is dull but constant and for bleeds that are relatively minor but have caused some mobility problems that will require a little time to heal. Spiking and blinding pain (deep muscle bleeds from injury) often requires me to reach out and share my struggles, perhaps take a pain pill or two, and seek some relief. It's hard to be mindful while battling the sting of acute pain. However, I find if I deliberately engage in deep-breathing exercises and stay connected while avoiding allowing my mind to wander and unhinging from false perceptions, the pain is much better controlled.”

Stress Management Training. If your pain level is high, your stress levels probably are, too. This training helps you maintain a routine schedule for activity, rest, and medication. It incorporates exercise or physical therapy into your daily routine, and trains you to keep a positive outlook.

Hypnotherapy. Therapeutic or medical hypnosis directs your focus inward to help you relax and reduce pain and anxiety. You can learn self-hypnosis from a trained hypnotherapist.

Counseling. Individual, family, or group counseling with a professional trained in pain management can provide emotional support and guidance. Tina Battillo, mother of two young children with hemophilia A, notes that anxiety is a type of pain: “Most of my boys’ pain is anxiety-related. It causes discomfort. I feel my children are more anxious than non-hemophilic kids because they associate injury with the added step of factor.” Matt Rollins adds, “Speaking with a mental health professional and learning meditation helped me the most. I can’t tell you how at peace I became when my mind accepted the fact that pain is part of my life and I can turn it into power and motivation to help others.”

Acupuncture. Many patients report pain relief from this ancient Chinese technique of inserting and manipulating thin needles into specific points on the body known to control pain pathways.[2]

Dozens of other therapies, including acupressure, massage, and chiropractic manipulation, may help control pain. Transcutaneous electrical nerve stimulators (TENS) deliver electrical impulses to interfere with pain transmission. Ultrasound therapy warms joints internally to provide pain relief, and laser treatments may provide relief in a similar way.

A good management plan for chronic pain must be personalized. It should use a multimodal approach, which addresses the psychological component of chronic pain by treating depression and reducing anxiety and stress. A multimodal approach includes *adjuvant* therapies (antidepressants and anticonvulsants); an exercise and/or physical therapy component; and some form of CAM, which allows the person to manage moderate to severe chronic pain with the lowest possible dose of painkillers.

Here’s how Maxwell Feinstein, a person with hemophilia A, sums up personalized pain: “I’ve had to learn to understand my pain in ways that were perhaps discouraged at an earlier age. Pain is a friend; it’s part of me. I’m learning from it every day and learning to live with it makes it less of a burden.”

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1. mbirmingham.blogspot.com
2. Acupuncture is safe for people on prophylaxis. National Hemophilia Foundation (NHF) advises that if you’re considering acupuncture, first talk to your hematologist or the staff at your HTC.

PING at the Zoo

Our Parent Information Networking Group (PING) meeting took place on December 4th, 2021 at the Durham Lodge at Henry Doorly Zoo. We kicked off the PING party with breakfast and a little icebreaker game. Alice from Optum taught us about joints and muscles, what happens with joint bleeds, the way joint bleeds affect the body, and how target joints are formed. We drew on ourselves or others with body markers to illustrate joint bleeds. We also met a macaw parrot, and learned some facts about macaws. Families were free to enjoy the rest of the day at the zoo and learn all about animals. We'd like to than our sponsors, Optum, CSL Behring, Novo Nordisk, and ARJ for sponsoring this event. Look for another PING event coming to you in

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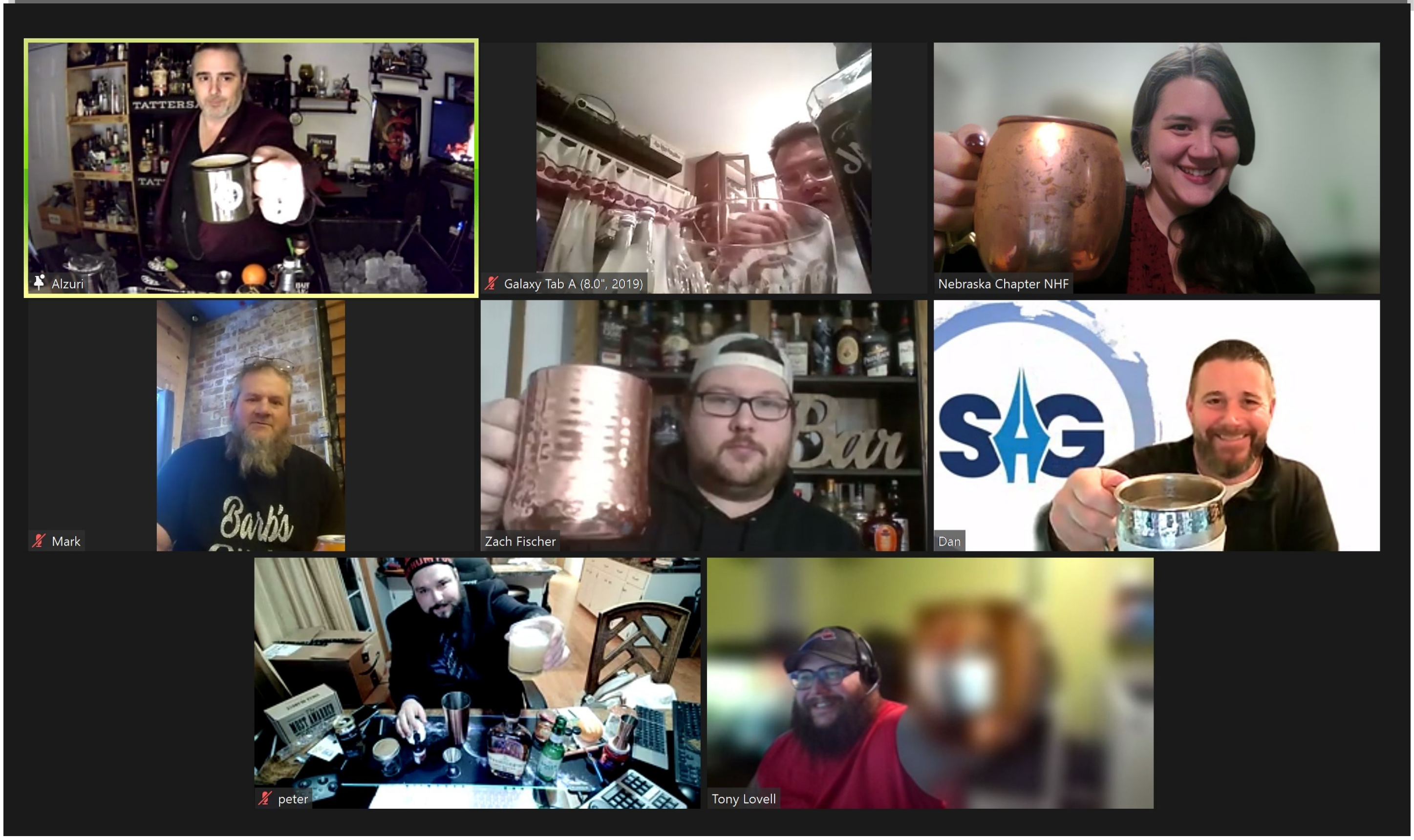
Virtual Men's Mixology & Mental Health Class



Would you believe we got a group of guys together for a virtual event and they had a GREAT TIME?! This year we added two adult men's programs and our final event of 2021 was for the guys. We hosted a two part virtual event focusing on mental health and some great cocktails. Mosi William joined us as our speaker on behalf of NHF and presenting on 'Talking about What Isn't Talked About', offering support and self care strategies for both caretakers and affected men alike. It went over very well and it was agreed that it was a topic that is needed among more men.

After Mosi finished, we welcomed Alzuri from Spirit World to teach us how to make a couple craft cocktails including the classic Old Fashioned as well as a Kentucky Apple Mule. The cocktails were delicious and the conversation was engaging around bourbon, whiskey, life and planning on new ways of reconnecting. I don't believe it'll be the last time these guys will willingly log into a Zoom call!

This event was made possible with funds from the Hemophilia Alliance Foundation. We look forward to more men's programs in 2022.
If you have an idea for an event, please let us know!

Nebraska Chapter Board Update

Outgoing Board Member– Ann Foster

Ann Foster of Gothenburg, Nebraska has spent the last four years serving on the Board for the Nebraska Chapter of NHF. She hosted two in person satellite walks, attended Washington Days, served on our advocacy committee and brought great insight and vision to the Board and the Chapter. Ann is stepping down from the board to pursue her Doctorate degree. She is passionate about the bleeding disorders community and advocating for her son, father, uncle, and herself while supporting the chapter and it's mission. Thank you for the last four years of service Ann. The chapter is stronger because you supported us.

Incoming Board Member– Zach Fischer

Join us in welcoming Zach Fischer to the Nebraska Chapter Advisory Board of Directors, starting in January 2022.

My name is Zach Fischer, and I grew up in the Chicago suburb of McHenry, Illinois. I have Hemophilia A with a mild severity. I grew up an avid sports fan and played a number of them including golf, baseball, soccer, swimming, water polo, and even full contact tackle football for a few years. I attended the University of Nebraska – Lincoln where I received my degree in Spanish. After college I began my career in law enforcement as a dispatcher at the University of Nebraska – Lincoln Polce Department. After 5 years of service in Lincoln, I accepted a promotion as a Dispatch Supervisor with the University of Nebraska – Omaha and the University of Nebraska – Medical Center Department of Public Safety. I purchased a house in Omaha back in December of 2020 and love doing DIY projects around the house. I also enjoy golf, hanging out with friends, and am an avid home brewer.

Board Member Needs

The Nebraska Chapter of NHF is looking to expand our Advisory Board of Directors. We are currently recruiting both affected and unaffected board members. We specifically are looking for members with diverse backgrounds including those who reside in rural areas, Spanish speaking or bilingual, individuals comfortable in the rare disease space, those with financial or accounting backgrounds, community connections or a knack for fundraising. This list is not exhaustive. If you know someone who would be a good fit for our Board and Chapter, please reach out to Maureen at mgrace@hemophilia.org.

Additionally, there's always room on committees for non board members at all. If you want to get involved and help with Advocacy, Programs and Education, Fundraising and Events or more. Please reach out.

Remembering David Taylor

David Tyson Taylor DDS was born on November 7, 1947 in Lincoln, Nebraska, the fourth child of Stephen and Alma Taylor of 1539 "D" Street. He was a survivor, and that was his mantra. He was born with hemophilia, and his parents were told he would not likely survive to his 12th birthday. But he did. He lived to nearly 74, and he lived those years with tenacity and amazing spirit.

David attended Capitol Elementary, Everett Jr. High, and graduated from Lincoln High School in 1966. He enrolled as a Freshman at the University of Nebraska that fall, then decided to try a few other endeavors the next year. One was working in a Dental Lab, and at that point, set his sights on becoming a Dentist. He achieved that goal in 1975. In the meantime, he pledged Theta Chi fraternity, met Donna Jamison on a blind date in 1968, and married her on November 22, 1969 at First Plymouth Congregational UCC. They moved to Omaha shortly after they were married and to Boone, Iowa following Dental College graduation.

Two years after joining a general dentistry practice in Boone, David announced he wanted to teach and was accepted to a graduate program in Prosthodontics at Marquette University in Milwaukee, Wisconsin. One month after the move to Milwaukee, David and Donna were blessed by the birth of twin daughters, Laura and Jill. And two years later, the family moved back to Lincoln where they settled in for the next 32 years.

During the Lincoln years, David taught Prosthodontics at the University of Nebraska College of Dentistry in addition to managing a private practice. He was very involved in the hemophilia community and became the first president of the Nebraska Chapter of the National Hemophilia Foundation. He served as Moderator and on various boards for Vine Congregational UCC. He sang in the Vine choir as well as with Lincoln Civic Choir. He was able to fly down the ski slopes in Colorado on a monoski, thanks to the Winter Park Disabled Ski Program. Table tennis became a passion as well as sailing. Eventually, he acquired a 22-ft. Catalina sailboat he appropriately christened the "Free and Clear". He raced with the Holmes Lake and Branched Oak Sail Clubs, serving a term as Commodore for each. Neighborhood bridge, backyard homemade ice cream and family gatherings and celebrations too numerous to count filled his days. In 2006, he and Donna became grandparents to Claire, followed by two grandsons, Caelan and Owen in 2009.

David experienced a lifetime of health issues, beginning in childhood with hospital stays and days of missed school due to bleeds. As he reached adulthood, treatment for his hemophilia improved, but danger lurked in the life-saving transfusions he received. He somehow escaped HIV, unlike most of his hemophiliac peers and family members, but he did acquire Hepatitis C. This destroyed his liver, and he underwent a liver transplant in 2007. His quality of life improved significantly following the transplant. In fact, the transplant essentially "cured" his hemophilia. But in 2012, a year after he and Donna moved to Parker, Colorado, he was injured in a bicycle accident, sustaining a Traumatic Brain Injury. Several strokes followed this, and David eventually became bedridden. Throughout it all, he kept going. He was not a "woe is me" person. He would be knocked down by circumstances beyond his control and sometimes because he took big risks. This may, in fact, have been why he never gave up.

David passed away on October 26, 2021. He is survived by his wife of nearly 52 years, Donna, his daughters, Laura Taylor Buntemeyer (Jay) and Jill Taylor Jesch (Brandon), three grandchildren (Claire and Caelan Buntemeyer, and Owen Jesch), brother Martin Taylor (Judy) of Grand Island NE, sister-in-law Julie Taylor of Endicott NY, and brother-in-law Doug Jamison (Angie) of Randolph IA and numerous cousins, nieces and nephews. He was preceded in death by his parents, Stephen and Alma (Tyson) Taylor, sister Joyce Taylor Donlan and brother James Martin Taylor. And it was this family he deeply loved.

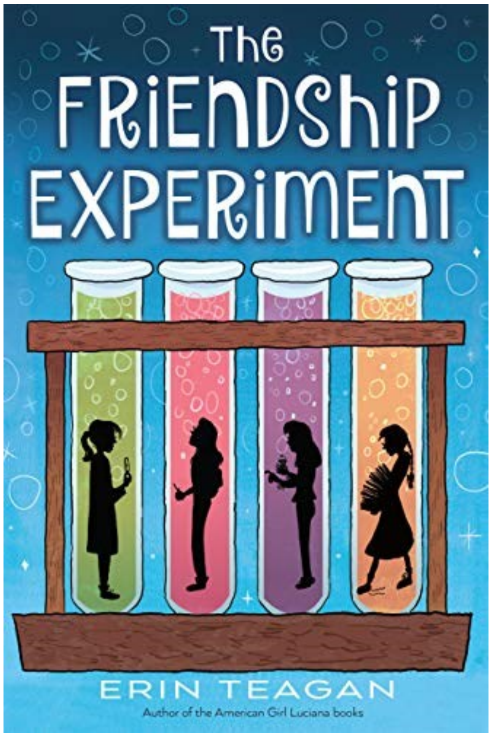
Interesting Fictional Teens

By Richard J. Atwood

Do you ever wonder whether teenage fictional characters with bleeding disorders can foreshadow the future of our community? I pondered this question because some recent novels caught my attention. These novels include young protagonists with bleeding disorders who may represent the next generation of leaders. Decide for yourself if the following novels provide any insights.

The Friendship Experiment

Erin Teagan
Houghton Mifflin Harcourt, 2016



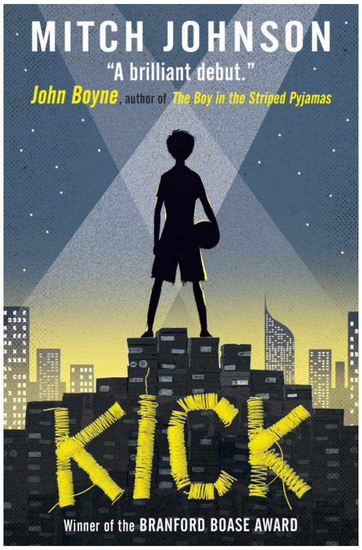
In this young adult novel (also appropriate for adults), Madeline Avery Little, or "Maddie," aspires to become a microbiologist, just like her deceased grandfather. Now in the sixth grade, Maddie conducts experiments. And her father conducts research on von Willebrand disease (VWD) at the local university, partly because it's personal: VWD runs in the family. Both Maddie and her older sister have VWD. Maddie keeps a medical diary (logbook), wears a medical bracelet, treats herself with a nasal spray, and worries that laughing could cause a nosebleed. She creates a crisis in her father's lab due to her negligence, and then she loses the friendship of her classmates after they read her personal notebook with its nasty comments about them. Maddie's sister self-medicates with Maddie's medicine, causing a medical crisis requiring hospitalization. Overwhelmed, Maddie realizes she needs to fix her messes with "I'm sorry." She also learns that there is no such thing as a "friendship experiment," because life is too complicated and too unpredictable. The author received expert advice to accurately portray VWD.

Based on these fictional characters, the future of our community seems promising. All the young protagonists with bleeding disorders who are depicted in these novels share a trait: they have a passion for what they do, whether it's sports or science. And there is tension or conflict that the fictional characters overcome. That explains each story's drama. Explaining vampirism is more difficult.

Teen Fiction Continued

Kick

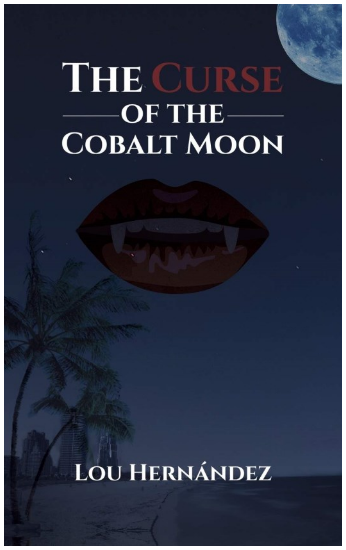
Mitch Johnson
Usborne Publishing, 2017



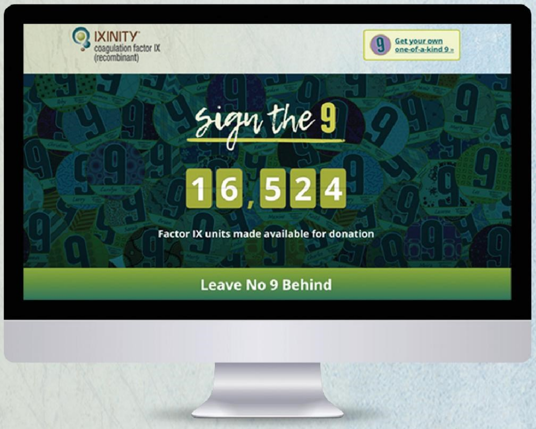
Budi, who lives in Jakarta, the capital of Indonesia, is almost 12 and small for his age. He no longer attends school, and now works in a factory sewing together football boots—shoes for exportation that he can't afford to buy. Budi loves football ("soccer" in America) and dreams of becoming a professional footballer. Yet he shares a family curse. Along with his grandfather, his father, and his dad's twin brother, Budi has a bleeding disorder—his blood doesn't clot properly. Budi's mother treats his skin cuts with coconut butter. Budi fears internal bleeds. He gets in trouble with the local slumlord, who wants to steal a shipment of football boots and use the shipping container for human trafficking. During the botched crime, and in the aftermath of an earthquake, both the slumlord and Budi's uncle are killed. Yet Budi ends up with all the trafficking money, which he unselfishly gives to a friend. Budi's bleeding disorder is never identified, but a poorly educated boy in a developing country who can't afford healthcare may not be correctly diagnosed and treated.

The Curse of the Cobalt Moon

Lou Hernandez
Austin Macauley Publishers, 2019



Rodolfo Josue Puig, who goes by "Joshua" to fit in, is a high school junior living in South Miami. Born in Cuba, Joshua was only nine when he was specially airlifted with other Cuban children to America in 1960. With no family members to help him, Joshua lives in a foster home. He loves playing on the varsity baseball team. Like his grandfather, Joshua has hemophilia that he treats with a daily injection of fibrinogen. After a fight with a teammate, Joshua is suspended from the school baseball team for his hemophilia, not because of the altercation. From a classmate, also from Cuba, Joshua learns that he is a docile half-vampire because his human mother married a vampire. On the hunt night of the cobalt moon, hostile half-vampires (having a human father and vampire mother) drain the blood from docile half-vampires to become full vampires. Joshua and his classmates (some are also docile half-vampires) make many fatal errors of judgment while fleeing for their lives, but they eventually escape. Apparently, being a docile half-vampire improves baseball skills and reduces the bleeding due to hemophilia. The treatment of hemophilia seems inappropriate for the 1960s, and the genetics of vampires is never fully explained.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Updated Event and Program Guidelines

NHF is committed to ensure the safety of our staff, volunteers, and the community we serve. These NHF Event Guidelines are one way for us to demonstrate that commitment.

As of October 1, 2021- In order to attend an in person NENHF event you must show proof of vaccination or a negative Covid test within 72 hours of the event. This is for any attendee 12+. Children do not need a negative covid test but still will need a mask for indoor events.

- **Stay Home When Appropriate**
  - Do not attend any program or event if you have tested positive for COVID-19, are waiting for test results, have any COVID-19 symptoms, of if you've had close contact with someone who has tested positive within the last 14 days.
- **Social Distancing**
  - Maintain social distancing with those not in your household. We are currently not encouraging handshakes or hugs.
- **Masks**
  - Masks will be required at all indoor NENHF events for the remainder of 2021.
  - Masks must be worn over your nose and mouth.
  - Masks are not required for kids under 2 years old, anyone who has trouble breathing or anyone who is unconscious or unable to remove a mask without assistance.
  - At this time, all persons will be asked to wear a mask regardless of vaccination status.
  - Masks will be made available by NENHF at all programs for adult and children.
- **Temperature Checks**
  - Temperature Checks will be taken at event check in and registration.
  - Temperature must be below 100.4 according to CDC Guidelines
- **Hand Hygiene**
  - Wash hands often for 20 seconds.
  - Hand Sanitizer will be made available at all programs and events.
- **Behavior Agreement**
  - All attendees 16 and older will need to sign a Behavior Agreement and COVID-19 Agreement to abide by all Guidelines at events or you will be asked to leave.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

FINANCIAL AID

HOW NENHF CAN HELP IN 2021 and beyond!

The Financial Assistance program is part of NENHF's continuing effort to improve the quality of life of individuals and families affected by bleeding disorders by providing financial support. Families can request up to $500 per year of support.

Example eligible expenses include, but are not limited to, the following:

Expenses incurred in the care, treatment, or prevention of a bleeding disorder
Transportation services to medical appointments and HTCs
Medical supplies not covered by insurance
Basic living expense emergencies (rent, mortgage, utilities, food, etc.)
Unexpected home or car repairs
Medic Alert Bracelets
Dental expenses
Health insurance premiums

Find more information and apply at: https://www.nebraskanhf.org/support-resources/financial-assistance-program.html

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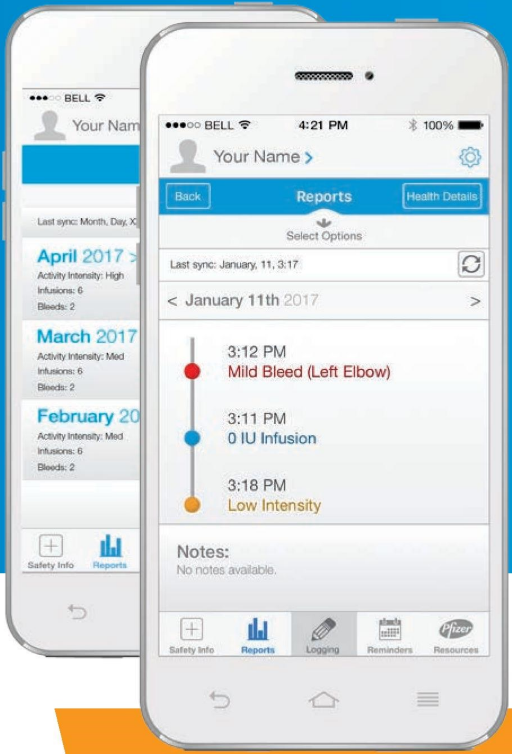

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Your Name >

Back Reports Health Details

Select Options

Last sync: January, 11, 3:17

< January 11th 2017 >

3:12 PM
Mild Bleed (Left Elbow)

3:11 PM
0 IU Infusion

3:18 PM
Low Intensity

Notes:
No notes available.

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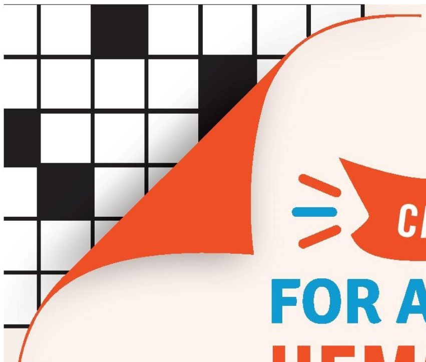
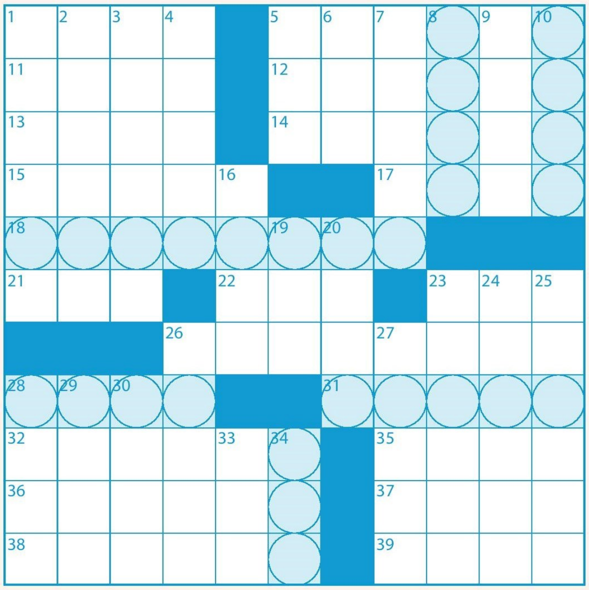
PP-HEM-USA-0692-01 January 2017



CAN YOU SOLVE

FOR A DIFFERENT HEMOPHILIA A TREATMENT?

Test your HEMLIBRA knowledge



ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for hemophilia A*

*According to IQVIA claims data from various insurance plan types from October 2019 to November 2020 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the _____ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers
32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin
16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. _____ thousand patients have been treated with HEMLIBRA worldwide†

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelet, 35. Otoe, 36. ariose, 37. tall, 38. lessen, 39. oles
Down: 1. catchy, 2. adorer, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

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† Number of people with hemophilia A treated as of February 2021.

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

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
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

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