BIG RED FACTOR

2020—Issue 4

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NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

Patience in a Pandemic

Thank you from the bottom of our hearts for being patient and understanding as the whole world shifted around us this year. We know it's been difficult for everyone, some more than others. Everything changed in March, right before we were set to have our first in person event in 2020. That means we haven't seen any of you all year. Let me tell you that:

WE MISS YOU!!

We really do. We have tried to shift programming to meaningful virtual platform. We've had successes and we've also learned what doesn't work as well. We don't know when life will return to 'normal' but we know that we can't wait until it does. What we do know is that while we wait for that to happen, we are committed to making our virtual programming better, more engaging and as accommodating as possible for our entire Nebraska community. We have seen people participate in our virtual events that have never been to a chapter program before which is outstanding. Virtual Programming will likely never leave us completely, as we have found what a great tool it can be.

We know that 2020 was awful and we are hoping for a less awful 2021. Our calendar has shifted to accommodate changes and we are constantly learning how to make our virtual programming better. Thank you for trusting us, for being patient with us and for getting through this pandemic. We are here for you always.

Happy New Year from Maureen, Misti and the Board

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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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.

2021 Events

All events through June 2020 will be virtual. We hope to be in person as soon as we believe it is safe. Keep up with events on our website, Facebook and through text.

Save the Date

March 2021
Teen Advocacy– March 18th
Advocacy– March 23-24th

April 2021
Spring PING– April 4
Adults with Bleeding Disorders Conference– April 24th

June 2021
Family Camp– June 4-6

August 2021
Virtual Bleeding Disorder's Conference– August 26-28th

September 2021
Family Education Weekend– September 18-19

October 2021
Unite Walk– October 2
FAB Women's Retreat

combined health agencies drive
MEMBER CHARITY

Co Pay Accumulators– What you should know

What is a Co-Pay Accumulator or Accumulator Adjuster Program?

These are programs that Pharmacy Benefit Managers (PBM) provide to the marketplace plans or large self insured empoyers. This affects patients who utilize a drug co-pay card or assistance from manufacturers to help cover the cost of factor products. With a Accumulator Adjustor Program, your pharmacy will accept the co-pay card or manufacturer assistance but since the funds do not come from you personally, they are no longer counted toward your out of pocket costs or your deductible. The PBM will utilize the full amount of the co-pay card but there is no longer any assistance to the patient to cover the cost of your out of pocket or deductible when receiving your factor. You will still be responsible for co-pays until your out of pocket max is reached on your own, without assistance from the Manufacturer.

What does this mean for me?

More and more health insurance plans have adopted the Co-Pay Accumulator model heading into 2021. Your new plan may have an adjustor program without you realizing it. If you rely on co-pay assistance from your manufacturer this likely will affect you in 2021. The PBM will accept your copay card and utilize it until the funds run out, likely a couple months into the year. As soon as this co-pay card runs out, you will then be responsible for the cost of your medication, co-pays and other associated costs until you hit your deductible. With an accumulator adjustor plan, the co-pay card now saves your insurance company money but not you.

What should I do?

Check with your employer or marketplace plan to see if there is an Accumulator Adjuster program in your plan. There are a lot more plans this coming year that have these programs written into them. If you have always relied on the co-pay cards to cover your deductible for Factor, know there are patient assistance programs that can help you with these new out of pocket expenses. Many chapters will be advocating to change or get rid of these programs within health plans. Get active with your chapter's advocacy efforts in the coming year to have your voice heard and to advocate for these programs to be reversed.

How can I learn more?

Check out this video at https://youtu.be/7ExMnOJs-h8

Or visit the HFA website for a great infographic on how Accumulator Adjusters affect patients.
Follow this link: https://www.hemophiliafed.org/our-role-and-programs/assisting-and-advocating/policy-priorities/accumulator-adjustor-programs/

UNITE DAY! Recap

On Saturday, October 10, the Nebraska Chapter of the National Hemophilia Foundation held our annual UNITE for Bleeding Disorders Walk, virtually. Though we were unable to join together in person due to our country's current climate, we were able to come together as a community to raise over $26,000 of our $40,000 goal for the year.

The virtual event began at 10am with a welcome and opening remarks by NENHF Staff, followed by a video from our National Presenting Sponsor, Takeda, and introduction of our board members who were present for the event. Our chapter awards were exciting this year! Two of our top 3 fundraisers were under 10 years of age! Way to go, Amelia and Oliver!

After the chapter awards, board member Geri Murphy led us in the Pinwheel Ceremony before we closed out the hour-long virtual event. We would like to thank everyone who donated, raised money, sponsored and supported this year's Unite for Bleeding Disorders walk! We hope to see everyone in person next year!

Factor Club (Raised $500 or more)

Amelia Mickeliunas
Oliver Clinkinbeard
Peter Senior
Erik Clark
Ann Foster
Carl Clark
Jenny Mickeliunas
Sharon Clark
Lane & Paisley Henderson
Andye Nelson

Top Team 2020

CELEBRATING 35 YEARS

NEBRASKA CHAPTER
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Congratulations, Team Elliott!

Unite for Bleeding Disorders

2020 TOP FUNDRAISERS

AMELIA - TEAM ELLIOTT

OLIVER - OLIVER'S CLOTTING CREW

PETER SENIOR - TEAM SENIOR

CONGRATULATIONS TO OUR TOP FUNDRAISERS!

Unite for Bleeding Disorders

Your HTC at a Glance– Children's Hospital

Comprehensive Bleeding Disorder Clinic- Children's Hospital & Medical Center

The Comprehensive Bleeding Disorder Clinic (CBDC) at Children's Hospital & Medical Center was created to provide specialized care for patients with bleeding disorders. Led by pediatric hematologists James Harper, M.D., and Chittalsinh M. Raulji, M.D., our expert team specializes in the comprehensive care of children, adolescents and young adults diagnosed with a bleeding disorder.

The clinic's multidisciplinary team consists of pediatric hematology physician/nurse practitioner, clinical nursing, patient education specialist, physical therapy, case management social work and dentistry. The CBDC clinic allows for patients to receive comprehensive care all in one visit, with an aim to bring clinical trials to our patients.

We would like to introduce you to our team:

James Harper, MD,

Pediatric Hematology/Oncology physician and the current Director of the Nebraska Hemophilia Treatment Center. He has a special interest in comprehensive care for patients with hemophilia and bleeding disorders.

Chittalsinh M. Raulji, MD,

Pediatric Hematology/Oncology physician who has a special interest in coagulation and thrombosis, with special focus on hemophilia and bleeding disorders.

Lindsey Leyden, DNP, APRN, CPNP-PC/AC,

Pediatric Hematology/Oncology nurse practitioner who specializes in caring for children with bleeding and blood disorders.

Your HTC at a Glance– Children's Hospital

Amanda Whitman MSN, RN, CPHON

Pediatric Hematology/Oncology Patient Education Specialist who focuses on creating and delivering patient and family education.

Rebecca Mathine, PT, DPT

Sports Physical Therapist who focuses on early detection of joint problems and provides evaluation focusing on strength, balance, range of motion and gait analysis. She also provides education on safe sport options for this population and the importance of living a physically active life.

Becky Deibler, BSN, RN

Pediatric Hematology/Oncology Nurse Case Manager, who collaborates, assesses, evaluates, and advocates for services 'individualized for every patient and family.

Social Work: Pediatric Hematology/Oncology Social Work who assesses the psychosocial needs of each family to provide the specific support and resources needed.

Dentistry: There are very few dentists who specialize in pediatric dentistry and very few are comfortable with taking care of kids with bleeding disorders. By having dentistry present during clinic visits, we hope to provide a dental home for these children to anticipate future dental procedures and be proactive in dental care for bleeding disorder patients.

Children's
HOSPITAL & MEDICAL CENTER

Contact Children's HTC

402-955-3950

FAMILY EDUCATION WEEKEND









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Family Education Weekend Recap

This year's Family Education Weekend looked different than any we've ever had. Due to the pandemic, we had to transition to a virtual program. We had education and programming on Friday night as well as Saturday afternoon into the evening on the 14th of November. Education tops ranged from mental health to gene therapy, evaluating your insurance plans to dealing with persistent pain. Dr. Harper from the HTC gave us his update, talked about what's in the pipeline for our hospitals and patients. We wrapped up the weekend watching the inspiting story of Chris Bombardier climbing Mt. Everest with Hemophilia B in the film Bombardier Blood. We also hosted a scavenger hunt/game through Goosechase where you submitted great pictures and videos of our challenges while interacting with our sponsors.

Education and community are at the heart of what we do as an organization. We miss hosting in person events so much but we are committed to still providing you these opportunities while we are all safer at home. Thank you to all of our families who participated and logged in for out educational sessions. Thank you to our sponsors who believe in our programs and services even in the face of a pandemic. We appreciate your patience as we figure out how to make virtual programming engaging and interactive for you all. Family Education Weekend is our biggest educational event each year and we know how important it is to you.

We hope more than anything that we can meet in person for Family Education Weekend in 2021. We are tentatively planning for an in person event, knowing it may still have to transfer to a virtual event. We are keeping our fingers crossed, wearing our masks and socially distancing to help our chances and hope you are too.

Looking Outside the Insurance Box

Matthew Barkdull

If asked what comes to mind when the term "hemophilia" or "bleeding disorder" is mentioned, most would say something about uncontrollable bleeding or bruising. When it comes to how I see a bleeding disorder, I think of it equally as a genetic medical condition and a financial condition. Bleeding disorders immediately force individuals and families into the cold and confusing world of insurance, with all the foreign babble that accompanies it.

Because it's human nature to heavily rely on professionals (or even armchair experts) when we're unsure how to navigate through the landmines of insurance, families are at the mercy of good, poor, or "meh" advice. Please indulge a few personal flashbacks:

In 2002, I got my first salary-based position that provided several benefits, including health and life insurance. When my wife and I pored through the life insurance policy, we found that it was just enough to bury me in a plywood coffin when I kicked the bucket. Not knowing much about "how the real world works" in terms of life insurance, we scheduled a visit with my company's financial advisor. I told him that I'd like to purchase more life insurance. After I had answered some questions about my severe hemophilia diagnosis and an earlier kidney transplant, the advisor quickly said that I could not qualify for more life insurance. "Your best bet is to save a ton of money throughout your career!" he said, nailing that discussion closed.

As a result, I became a disciple behind the "Got a medical problem? Don't bother applying for life insurance!" philosophy. But I terminated my discipleship 17 years later, when a good friend and brilliant financial adviser contested my views, saying that there were many possibilities to protect my loved ones if I kicked the bucket. The upshot? If I pass away at age 65, my plan now guarantees that my beneficiaries will be mostly financially independent as they go on through life. Not bad for a guy who not only has severe hemophilia, but is a former three-year dialysis patient, recipient of two kidney transplants, cancer survivor, and severe West Nile Virus survivor—and has been infected with hepatitis C. My friend taught me the fine art of looking outside the box.

Another interesting experience involves medical insurance. I was born in the 1970s, when hemophilia treatment was still trying to get its footing, and when health insurance companies could cap coverage with lifetime maximums and limit or deny coverage because of the infamous pre-existing condition clause. Consequently, I was given the advice to always work for a company that was large enough to offer outstanding medical benefits and absorb the cost. It was unthinkable to venture off to be my own boss and start my own business, as my father had done throughout his life. I carried this belief until I lost my job at a company where I'd been employed for over 16 years. During my first year of unemployment, I tried without success to find another permanent job within a large company. For years, I had been contemplating a business idea, but never dared to pursue it because of my social and medical conditioning. As time went on without resources, I felt I was ready to go against the grain and open up my own organization, despite the hardship of not knowing how I'd ever cover my factor or my family's medical needs.

Looking Outside the Insurance Box, cont'd.

In the past, I had asked nonprofessionals and nonexperts about getting medical insurance as a small business owner. Their recommendations were all over the map. But when I started working with financial professionals, as well as experts within the hemophilia community, I became more and more comfortable, feeling there was more consistency in these recommendations. Being self-insured is a pricey ordeal with its own set of challenges, but after counseling with the executive director of my local hemophilia chapter, I was astounded at the resources she gave me. Pages and pages of resources, both in-house and outside of the chapter, showed me that I had little knowledge. The result? I was able to get my business underway, while national and local resources covered premium and deductible expenses to bless me and my family.

These are only two examples, out of dozens I could have used to illustrate important financial principles you need to understand when taking a step into unfamiliar territory—which is often saturated with misinformation, preconceived beliefs, and pop culture advice. The overarching financial principle I wish to emphasize: Always think outside the box.

A few recommendations that will aid you and your family:

1. Never accept a single opinion or recommendation at full face value.

Years ago, I was employed as the health officer at a very large, international nonprofit organization. One of my tasks was to work with worldwide medical institutions and other service providers to solve many kinds of problems patients were facing. During that time, I learned a valuable lesson: Never rely on one person's answer, opinion, or recommendation at full face value. This is different from assuming everyone is trying to snow or mislead us; they simply may not understand the full picture. This principle leads to the second principle.

2. Educate yourself.

And not just online, where everyone is taking a stab at a problem. Surround yourself with experts; get second opinions. It's okay to be persistent because often, even the most well-meaning professionals may not take as much interest in helping you as you do yourself. If you find a pattern of people answering similarly, you're probably receiving good advice.

3. Learn to ask questions.

I never pretend to know what I'm doing if I honestly don't know. So ask questions of those you're working with. If the financial or insurance expert is describing something with which you have little familiarity, feel free to ask questions as often as you need to. Most people find it helpful to set expectations early: "Hey, just a quick warning. I'm really a novice when it comes to insurance. I'll probably be asking a ton of questions to make sure I'm understanding everything. I'd assume you're cool with this." And most of the time, they are!

Insurance of any kind has become a necessity in our lives, especially within the bleeding disorder population. It's critical that we not only understand insurance, but that we learn to build a team and to advocate for ourselves and our loved ones. My experience is that when I've been willing to take a risk and reach out for information and support, I've never regretted doing so.

Matthew Barkdull, MBA, MS, LMFT, MedFT, provides education, assessment, coaching, advocacy, and support through his organization Wholeness Integrated Solutions, PLLC. WIS works with individuals, couples, families, and institutions to assess and empower problem-solving within the Eight Dimensions.

PING (Parent Information Networking Group)

Families from all over Nebraska joined us for our Virtual PING event on Saturday, December 5th. We watched a Challenge Accepted video with Genentech on Laughter in the face of Adversity, had a book reading with the Jolly man, Santa himself and listened to holiday music while crafting on Zoom with other particpants.

The kids read along with Santa with books sent to them in their PING package. Santa even let us do a Q and A where Santa answered questions about his favorite cookies, how Rudolf was and so many more. Thank you to our sponsors for supporting this virtual event and event boxes.

Happy Holidays!

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FINANCIAL AID

HOW NENHF CAN HELP IN 2020 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

HEMOPHILIA CAN BE DIFFICULT.

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Pfizer Hemophilia

Community Voices in Research– CVR

What is CVR?

Community Voices in Research (CVR) formally known as MyBDC, is a community-powered registry but most importantly it is a partnership between the bleeding disorders community and NHF. When enrolling in CVR you are adding your voice and your experience which in turn helps to determine the direction of research for our community!

The Power of Data

Your voice turns into deidentified aggregated data which provides necessary useful information! For example; collected data from your local chapter community can highlight the possible need for additional women's programming and provide the required data to apply for grants to fulfill that need.

Call to Action!

Have you registered for CVR and taken your baseline survey already? If not, we are talking to you, your Nebraska Chapter needs you! When you enroll in CVR and complete your baseline survey you are providing immediate valuable deidentified aggregated data for your community! Enroll Now!

Step 1: Take enrollment survey (2 minutes). Answer a few questions about you and how bleeding disorders affect you.

Step 2: Take baseline survey (20-30 minutes) by following the link sent to your email. It will ask you more detailed questions about living with a bleeding disorder. You don't have to complete it all in one sitting.

Step 3: Access your CVR Dashboard. Now you have access to everything CVR has to offer!

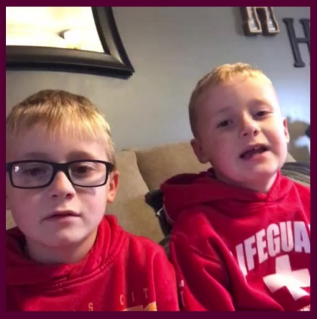
Ready to get started? www.hemophilia.org/cvr

Nebraska Chapter
National Hemophilia Foundation

TURNED 35

The Nebraska Chapter of NHF has been around since 1985.
In the last 35 years, we have helped and grown to help numerous families with bleeding disorders all across Nebraska and Western Iowa.
Thank you to our founders, Carl and Sharon Clark, along with every board member, committee member, volunteer, staff and the heart of our cause, our community for making NENHF the organization who gets to advocate for you, support research for your future and provide you with education and empowerment for living with a bleeding disorder. We hope someday to find a cure so you no longer need us. Thank you for trusting us and being part of our community. This bleeding disorder family is outstanding.






Depression, PTSD, and Inhibitors: My Family's Experience

Cazandra Campos-MacDonald

Everyone processes stressful events differently. Moving, starting new jobs, changes in relationship status, and financial hardships are among the most stressful events that people experience. Living with a bleeding disorder and an inhibitor is also a reality that can be extremely stressful. We wait to reach a certain Bethesda Unit (BU) to begin immune tolerance, access a port daily, and deal with bleeds that take a long time to heal. How we handle these problems can affect our outlook on life and can raise other concerns.

Diagnosed with an inhibitor at age 11 months, my youngest son Caeleb is now 14 years old. Many complications, including target joints and an allergy to factor VIII, resulted in a year when Caeleb spent more days in the hospital than at home. It was an incredibly stressful time for our family. As a second grader, Caeleb didn't easily understand why hemophilia was so difficult and painful. As his mother, I needed to remain calm to advocate for my son.

As a woman with clinical depression *(1)* and anxiety, I work hard to manage my mental health issues. During Caeleb's journey with an inhibitor, I found that writing was the best way to deal with my feelings. I blogged, posted on social media, and wrote articles that expressed my fears and anxieties. It was my process. My husband Joe is quite the opposite. When a problem arises, such as a terrible bleed that Caeleb endured, Joe gets incredibly quiet. He says he is a master "builder of walls," not allowing emotions to get the best of him. Joe and I work together exceptionally well as a team, but it wasn't until a few years ago that I discovered something remarkably interesting about my husband.

While I wrote my book about my experiences raising two sons with hemophilia and inhibitors, in the early stages of writing, Joe was my first editor. It often took some time for

him to complete a chapter because reading and reliving the experiences we had endured brought up emotions that Joe hadn't processed. He realized then that the situational depression2 he felt—which he had attributed to work issues and life in general—was partly caused by Caeleb's active struggles. Many years later, the lingering effects of these traumatic experiences continue to take a toll on our family.

What came next was the reality that post-traumatic stress disorder (PTSD) was now a part of our family. PTSD is a mental health condition triggered by a terrifying event. Our journey into the frightening part of living with an inhibitor began with Caeleb's repeated hospitalizations; with a team of nurses holding him down to access his port while he fought. Not only did the trauma of these hospitalizations and being held down for infusions affect Caeleb, but PTSD is also evident in my life, and in Joe's.

Depression, PTSD, and Inhibitors, Cont'd

Once the frequent hospitalizations ended, our family experienced fantastic freedom. However, the times we went to the hospital for regular clinic visits and blood draws triggered our PTSD. For us, the smells and sounds of the hospital are unlike those of any other places we visit, so walking into the building immediately raises our defenses. When Caeleb goes to the clinic for a blood draw, it takes him extra time to prepare himself mentally for the stick. He handles needles well, but the immediate physical response he can't help is fear. PTSD is an issue that affects our family, and memories of the traumatic experiences Caeleb endured come back in a flash.

Joe and I treat our depression with the help of medications prescribed under the careful supervision of a psychiatrist. Not all primary care physicians have a specialized understanding of the medications needed to treat depressive disorders; that's why Joe and I have a psychiatrist who can closely monitor our individual needs. The other component that helps us maintain good mental health is regular therapy. A therapist is a necessity on our path to good mental health. Often, people think that treatment is a sign of weakness. In my experience, I see therapy as a sign of strength. Struggling with mental illness can be frightening, but when working with a therapist, you develop the tools you need to get through the times when depression and anxiety can take over your life.

When left untreated, mental health issues can be overwhelming and prevent you from living your best life. Hiding your problems, hoping they'll resolve on their own, is not in your best interest. It takes a great deal of strength to admit that you need help. We all struggle, but often we just learn over time how to hide the issues we feel make us "weak."

COVID-19 has brought even more stress and anxiety to our lives, and this can lead to depressive episodes. If you deal with mental health issues, please know that you are not alone! Many people have the same challenges; yet many fear that revealing their issues will stigmatize them. True freedom comes when you lower your defenses and share your struggles with loved ones. Maybe you know someone in the bleeding disorder community who has mental health issues—especially someone living with an inhibitor. Reach out. Talk to them. Ask questions. If you're struggling yourself, they may be able to help you find the resources you need to get on track and work toward making your mental health a priority..

1. Clinical depression is a term often used to refer to one or more types of serious depressive disorders that may occur with or without the presence of a specific stressor (www.nami.org). 2. Situational stress can generate emotional or behavioral symptoms that look and feel very much like clinical depression (www.nami.org).

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

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

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

Genentech
A Member of the Roche Group

Being Better at Life

Derek Markley

I often wonder how our son Bubba can remain unperturbed in situations that would drive me to the brink of insanity. After navigating life for nine years with severe hemophilia B, Bubba's greatest source of recurring stress is losing games of Fortnite or FIFA on his PS4. His ability to stay calm in virtually every part of his life is a mystery to me. It's an understatement to say that I envy this part of his personality.

How does he do it? A recently released study from Italy1 suggests that people with hemophilia may be more effective at dealing with life's challenges and hardships than people who do not have a chronic condition.

The study included 84 participants with severe hemophilia and 164 who had no history of a chronic illness. The research team found that the percentage of individuals "flourishing" with respect to mental health, as measured by the survey instrument, was higher for the participants with hemophilia than the participants with no chronic illness.

Bubba is the only member of our family who knows what it's like to have severe hemophilia, and he has developed his own strategies for handling the challenges that come with it. While our son was not a part of the Italian study, elements of his personality lead me to believe that he will flourish, too. I think he will teach us a few things along the way. In fact, I'd like to think that we as parents have also become more understanding, and more open to increasing our knowledge of the challenges people face daily. I was perfectly happy believing this to be true, and felt no need to have my belief tested.But life doesn't work that way…

Last summer my wife Ashley spent 11 days in the hospital, with five of those days in ICU. She suffered from severe acute necrotizing pancreatitis. Her condition was incredibly serious, and I had an uncomfortable discussion with a physician about mortality rates. We were very fortunate that Ashley made it through despite significant damage to her pancreas. Her physician warned us that her recovery could take up to a year, and that we shouldn't expect things to be "normal" in the near future.

In December 2019, Ashley began experiencing significant weight loss, nausea, loss of balance, and a number of other issues. Labs during a trip to our nurse practitioner indicated that Ashley's glucose level was over 400. A person's glucose level should be under 140 two hours after eating. We were immediately sent to the local ER, where we learned that Ashley was suffering from diabetic ketoacidosis. At age 39, my wife was diagnosed with type 1 diabetes. After three days in ICU and another three days in recovery, Ashley returned home as a diabetic for the first time. She will be insulin dependent for the rest of her life.

During Ashley's time in recovery, Bubba watched her check her sugar levels and inject insulin. His response was understated, as usual: "At least I'm not the only one who gets stuck with needles now."

Being Better at Life, cont'd.

Everyone had a quick laugh, including the nurse. It was good timing on Bubba's part.

A week later, Ashley and I met with a diabetes educator. At one point, the educator asked me if I would be able to give Ashley an emergency injection of glucagon if necessary. My wife and I both smiled and laughed. Our diabetes educator was clearly confused. I explained that we had a son with severe hemophilia and that we did weekly infusions at home. The idea of mixing medicine and a subcutaneous injection was not very intimidating.

That was the moment when I realized how much we'd grown as a family. In the midst of learning about Ashley's lifetime of treatment, we could both find the humor in a question about our ability to give an injection. Neither of us had spent the past nine years as a person with hemophilia, but living with Bubba had taught us a lot. Part of our learning curve included ports, infusions, sterility, and the physical treatment of issues related to his bleeding disorder. That was only part of our growth and development.

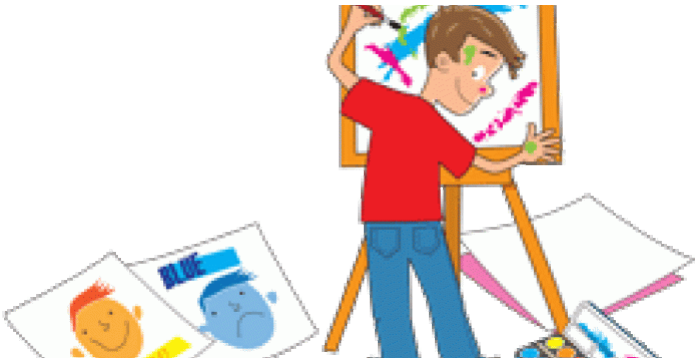
Being Bubba's parents taught us how to deal with our emotions when health-related issues occurred. Bleeds can be scary. Surgeries cause significant stress. Raising a child with severe hemophilia meant that we experienced high levels of emotion and stress on multiple occasions. We learned how to focus on the well-being of our son, not on all the other things surrounding his condition. We grew in our ability to more fully understand the impact of a medical condition on individuals and their immediate family members. Hospital trips, needles, and monitoring a loved one's condition were simply parts of our normal life. Most people would not characterize any of this as normal, but it's what we do daily as a hemophilia family. We have learned how to persist and work through challenges.

I do not have hemophilia, nor do I have diabetes. I can say, with great assurance, that hemophilia taught our family how to flourish when faced with a significant challenge. Without Bubba's presence in our life, I'm certain that a diabetes diagnosis would have been far more difficult. We're a little tougher because of what we've learned as Bubba's parents. I know that Ashley is more confident in her ability to move forward managing her diabetes because of our experiences. I don't have a study to prove it, but I'm pretty sure we get a little better each day.

Derek lives in Saltillo, Mississippi, with his wife Ashley and their children Abbey and Bubba. He is the executive director of two University of Mississippi regional campuses and an assistant professor in the School of Education. Ashley is a fourth-grade math teacher in the Tupelo Public School District. Derek is the author of The Bubba Factor, available on Amazon in Kindle format and in paperback..

1. Luca Negri, Andrea Buzzi, Anna Brigida Aru, et al., "Perceived Well-being and Mental Health in Haemophilia," Psychology, Health & Medicine, Jan. 26, 2020.

Kid's Corner: Artistic Fun!



Art Therapy for Kids with Bleeding Disorders

You can express your thoughts and feelings without talking. There's a different way of sharing how you feel about living with a bleeding disorder, and it can be fun. It's called art therapy.

If you're ever feeling sad, mad or scared, it's important to be aware of it and then figure out how to handle it. The same goes for happy feelings, like excitement, thankfulness or love. Art therapy helps you let stuff out and get your creative juices flowing.

Instead of using words, you grab a brush, a sponge or even a pencil, and pick colors that match how you feel. You can also mix a few colors to create a whole new color. Then, let the lines, shapes, textures or whatever else you feel come out on the paper or canvas.

If you're new to art, this may feel strange. Here are some tips to get you started:

Ask a question

Ask yourself a question, like: "How did I feel during my last joint bleed?" or "What was I thinking when that kid at school made fun of me?" Then show it in your art project.

Create a collage

Cut out pictures and words from old magazines that show how you feel. Paste them together in a colorful collage.

All artists invited

Art therapy is not about creating something beautiful or perfect; it's about showing your feelings. No one's grading you or judging you.

Free your feelings

Be open to whatever thoughts or moods come out. Art therapy can help you not only express your feelings, but also discover them.

Sharing and caring

When you're ready, consider sharing your art with someone who can help you work through any feelings that concern you. That person could be your mom, dad, grandparent or the social worker at your local hemophilia treatment center (HTC). Some HTCs even offer art therapy to patients.

So open up to the artist within you. It will help you express your feelings creatively.

Author: Kadesha Thomas Smith

September 1, 2014; HemaWare Junior