

Reducing Screen Time: Your Mind and Body will Thank You!

Your Heart Your Life! Cold, Flu and Viruses How to Prevent Getting Sick

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### FROM THE EDITOR

**It's that time again.** School is in session, winter is upon us, and life is moving forward despite an unsurmountable list of challenges.



We are all forging ahead and doing our best to keep our family and bodies healthy and happy. In this issue of Infusing life, we discuss keeping our body healthy in the winter, helping keep our minds healthy by reducing screen time, and in our clinical corner keeping our hearts healthy by reducing our risk of heart disease.

At Brothers Healthcare, we sincerely wish the best for you, our readers and patients, during the upcoming holiday season and look forward to celebrating a healthy new year with all of you.

Stay healthy and safe, —Kelle Carthey, RN, Editor



INFUSING LIFE FALL 2021

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## PATIENT-FIRST PACT

At Brothers Healthcare, our patients' wellbeing is at the center of everything we do."



At **Brothers Healthcare**, our patients' wellbeing is at the center of everything we do. Here's an example from Linda Reyes, "One Saturday I was gardening with my husband and a patient reached out asking for a delivery of medication for his regular treatment which was due that day. I spoke with the pharmacist and he said,"Yes I will be there." He didn't tell me that he was busy with his family, but he dropped everything and came to the pharmacy to fill this order. I told him that I would deliver it to the patient which takes some time because I live about an hour from the pharmacy. So, both the pharmacist and I went above and beyond to make sure this young man got the medication he needed right away. That's what putting the patient first means to me." — Linda Reyes 🌫

## **CLINICAL CORNER**



ALTHOUGH HEART DEFECTS CANNOT BE PREVENTED, MANY HEART DISEASES ARE PREVENTABLE WITH A HEALTHY LIFESTYLE..." A healthy heart is crucial to living a healthy life. The heart is a primary organ in the body, helping to push blood throughout the entire system. The heart has the power to positively or negatively affect other bodily organs and systems, which is why your heart's health is essential to ensuring the body is functioning correctly.

According to the Center for Disease Control and Prevention, as of 2018, heart disease is the number one cause of death in the United States. However, heart disease can be preventable in certain circumstances with a healthy lifestyle. Brothers Healthcare created a short guideline on what you should know about heart disease.

### WHAT IS HEART DISEASE?

To begin, heart disease comprises of several cardiovascular health issues, which can include: **ARRHYTHMIA:** a disorder of the heart that causes abnormal heartbeats.

**ATHEROSCLEROSIS:** the narrowing or hardening of the arteries due to a buildup of plaque.

**CARDIOMYOPATHY:** a condition that causes the heart's muscles to stretch (Dilate), thicken (Hypertrophic), or stiffen (restrictive), making it unable to pump blood efficiently.

### CONGENITAL HEART DEFECTS:

causes heart irregularities that are presented at birth, affecting

the heart walls, heart valves, and blood vessels.

**CORONARY ARTERY DISEASE (CAD):** causes weakened blood flow into the arteries and is one of the most common forms of heart disease.

**HEART INFECTIONS:** can be caused by bacteria, viruses, or parasites.

The symptoms vary depending on the conditions, from shortness of breath, swelling in the feet and ankles, lightheadedness, fluttering heart, chest

## AS NEW EVIDENCE EMERGES, THE LINK BETWEEN DIET AND Heart disease grows stronger. What you put on your plate can influence every aspect of heart health."

pains, coldness, numbness, fatigue, and irregular rhythm.

### WHAT CAUSES HEART DISEASE?

The cause of heart disease can vary, so here is a quick breakdown of the causes of each condition.

**ARRHYTHMIA:** the common cause of arrhythmia includes coronary artery disease, diabetes, drug abuse, excessive alcohol or caffeine, high blood pressure, smoking, medication, stress, and valvular heart disease.

**ATHEROSCLEROSIS:** high cholesterol, poor diet, and aging play a role in getting atherosclerosis.

**CARDIOMYOPATHY:** there are several types of cardiomyopathies. First, dilated cardiomyopathy causes reduced blood flow from the damage of the heart, such as infections, toxins, or certain drugs. The second type is hypertrophic cardiomyopathy which is inherited or developed due to high blood pressure. Lastly, restrictive cardiomyopathy can be caused by diseases like connective tissue disorder or can occur for a known reason.

### **CONGENITAL HEART DEFECTS:**

typically developed in the womb and can develop while the heart is developing. As for a healthy person, sometimes the heart structure can change throughout someone's life, causing a heart defect.

**CAD:** the most common cause of CAD is cholesterol plaque building up in the arteries, causing vascular damage.

**HEART INFECTIONS:** typically caused by germs that reach the heart, such as bacteria, viruses, and parasites.

### WHAT IS THE RELATIONSHIP with heart disease and bleeding disorders?

Now how does heart disease affect those with a bleeding disorder? Heart disease is the top disease that kills Americans, but those with a bleeding disorder might have challenges treating cardiac issues.

HemaWare wrote an article in 2008 called "Heart Procedures and Hemophilia," discussing an individual's experience undergoing a heart attack. The individual was transported to a hospital and needed to undergo openheart surgery.

"Performing open-heart surgery on someone with hemophilia is no easy task. It involves significant collaboration between the hematologist and cardiologist before, during, and after the surgery. In addition, people with hemophilia typically need to receive continuous clotting factor infusion throughout the operation to prevent uncontrolled bleeding. They also need to be carefully monitored for bleeding issues after their procedure," according to Heart Procedures and Hemophilia.

The article discusses the lack of guidelines the medical institute had for individuals with a bleeding disorder. Although technology and knowledge about bleeding disorders have improved dramatically, individuals should still take precautions to ensure proper health.

"Patients with hemophilia may have lower cardiovascular mortality but have the same high prevalence of subclinical atherosclerosis as the general population. Furthermore, of all cardiovascular risk factors, hypertension is more common in hemophilia, which not only increases cardiovascular disease (CVD) but also the risk of intracerebral bleeding," according to the American Society of Hematology.

### HOW CAN IT BE PREVENTED?

Although heart defects cannot be prevented, for the most part, many heart diseases are preventable with a healthy lifestyle.

### HERE ARE SOME THINGS TO Know to help you get Started:

**NUTRITION:** To begin, practicing a healthy diet is critical to having a healthy heart. This is because nutrition can influence your body's blood pressure, cholesterol, and other risk factors. Still, eating leafy green vegetables, whole grains, berries, avocados, fatty fish, walnuts, beans, dark chocolate, and many more can help you maintain a healthy diet.

"As new evidence emerges, the link between diet and heart disease grows stronger. What you put on your plate can influence just about every aspect of heart health, from blood pressure and inflammation to cholesterol levels and triglycerides," according to Healthline.

Nevertheless, it does not end with having a healthy diet. Being active and exercising can also help prevent future heart issues.

**EXERCISE:** It is essential to keep moving, take a walk, or slow jog.

"Couch potato and desk jockey lifestyles seem to have an unhealthy effect on blood



fats and blood sugar. If you work at a desk, remember to take regular breaks to move around. Go for a stroll on your lunch break, and enjoy regular exercise in your leisure time," according to Healthline.

According to John Hopkins Medicine, beginning a workout regime can help lower blood pressure, weight control, strengthen muscles, stop or slow the development of diabetes, lower stress, and reduce inflammation.

Workouts such as weight lifting, yoga, dancing, walking, Pilates, riding a bike, or playing a recreational sport can all improve your lifestyle.

Lastly, it is essential to stay updated with annual screenings to check blood pressure, cholesterol, and sugar levels. Also, to speak to your hematologist about prevention measures for heart disease.

### **COVER STORY**



## YOUR MIND & BODY WILL THANK YOU!

"PUTTING DOWN YOUR PHONE AND GOING OUTSIDE OR DOING AN ACTIVITY YOU ENJOY CAN BE A MOOD BOOSTER. IT CAN MAKE YOU FEEL MORE ACCOMPLISHED AND IMPROVE YOUR WELL-BEING." Instagram, Twitter, Facebook, LinkedIn, You Tube, TikTok, and many more screens and apps can be consuming your time. At times, it might be challenging to put your phone down if you are looking at new recipe videos, make-up tutorials, influencers' profiles, or funny TikToks.

Nowadays, we are consumed by our phones more than we might think. If you look at your screen time setting on your phone, how many hours have you spent looking into a screen? It can range from 4 hours to maybe 10 hours a week. Screen time is not limited to phones either; it can include your laptop, iPad, or television.

In 2019, Scripps Health stated that the average adults spend about 11 hours a day staring at some screen or electronic device. However, some people cannot help being on a device for so long because of their careers. Still, there are several ways to reduce your screen time.

### WHY SHOULD YOU REDUCE YOUR SCREEN TIME?

First, let us understand why a significant amount of screen time can negatively affect your mental and physical health. According to Scripps Health, an excessive amount of screen time can cause eye strain, headaches, insomnia, poor sleep, social media addiction, neck pain, shoulder pain, back pain, tendonitis, carpal tunnel, and a sedentary lifestyle.

Significant screen time can also mean you are disengaged with someone or missing out on an experience. Although people can be connecting with others through social media, it is not the same as connecting with others in person. Disconnection can lead to loneliness, depression, or anxiety. By starring at a screen for too long, we miss out on life.

### **SCREEN TIME FOR CHILDREN**

With the pandemic, many of us have found that technology helps to keep us occupied, especially with children. Although it is nice to distract children by watching YouTube videos or playing games on the screens, it should be in moderation.

Many studies on children and screen time are being done because researchers are unsure if excessive screen time alters children's brains. The American Academy of Pediatrics provides a guideline about screen time: children under 18 months old, no screen time. Parents should choose only high-quality media for children 18 to 24 months old and watch it with their children. Finally, for children 2 to 5 years old, less than one hour per day of high-quality programming is recommended, with parents watching along.

There are also some steps that parents can follow to help reduce screen time for their older children. One being, to set a technology-free zone, meaning when it is dinner time, no one brings their phones to the table. In addition, there are parental control tools that can help limit content on children's phones or other devices. It is essential to explain to the child why you have decided to limit their screen time.

Besides being on the phone, a parent can encourage children to do other activities such as playing outside, reading a book, or playing a board game. Also, limiting the number of screens in the child's bedroom is essential, ensuring they do not have their phones before bed. To find more tips on limiting your child's screen time, you can visit verywellfamily.com, where they explain other tips and tricks on reducing technology usage.

### HOW TO LIMIT YOUR SCREEN TIME

Although it might sound easy to limit your children from using their phones too much, it can be difficult as an adult. As adults, we need to text people, send emails, and generally do work using technology. However, individuals can still practice limiting their recreational screen time.

Typically, in your phone settings, you have an option to limit screen time at a specific time or for a specific amount of time. For example, individuals can limit screen time to two hours before bed or an hour after waking up. They can also set time limits for how long they can use specific apps in a given day. Again, the preference is on the individual, but less screen time means more time to focus on yourself.

"Late-night screen time can

sabotage your sleep in a couple of different ways. Scrolling through social media posts, playing Words with Friends, or doing other activities on your phone will stimulate your brain and keep you from settling down for the night. Plus, the blue light that your phone emits can suppress levels of melatonin, which is a hormone that controls your body's sleep-wake cycles," according to HemaWare.

Nowadays, many people are working from home and constantly are looking at their computers. It is essential to look away from the screen for 10 minutes to give your eyes a break. Standing up to stretch or focusing on your posture can help you feel better while working on the computer.

Finally, creating activities for yourself where you do not need a phone can be the key to reducing screen time. For example, physical activity such as working out or even going for a walk without checking your phone can help boost your mood or improve your mental and physical health.

"Putting down your phone and going outside or doing an activity you enjoy can be a mood booster. It can make you feel more accomplished and improve your well-being. Depression and anxiety can cause a person to withdraw and isolate themselves from others. Engaging in social activities helps you connect with others and improve symptoms of these conditions," according to the Mayo Clinic Health System.

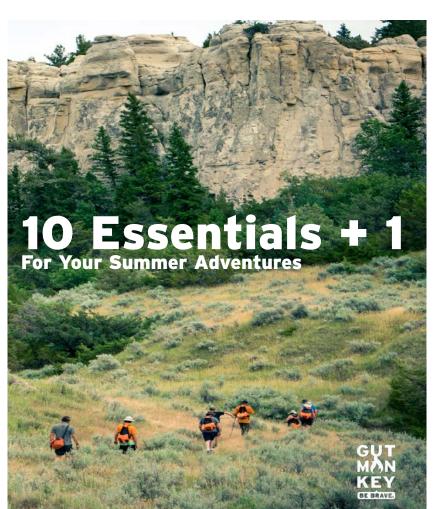
### WHAT ARE THE BENEFITS OF LIMITING SCREEN TIME?

Reducing your screen time can help your overall mental, physical, and emotional health. It can motivate you to become more active and help improve a relationship with a friend or family member. Overall, it can encourage you to be in the moment, enjoying what life has to offer while you are not looking down staring at a screen for hours.



Here's a friendly reminder to play safe in the outdoors this summer. We're all excited to get outside and make the most of the warm weather. Be responsible and pack these 10+ Essentials the next time you venture off the beaten path. Remember to carry with you any important treatment supplies and know how to use them.

GutMonkey provides live and virtual experiential education for the Bleeding Disorders Community. Between keynotes, expeditions, and summer camps, we're ready for a brave and safe summer. Visit GutMonkey.com to learn more.





# SEASO

**D** & F

HOW TO HELP PREVENT GETTING SICK IN THE WINTER

"Healthy adults can expect to have two or three colds each year..." The winter season is beginning to unfold, and many correlate the season with the holidays, snow play, and, unfortunately, cold and flu viruses. Generally, in the winter, people tend to get colds or cases of the flu due to many different factors. According to research, weather changes can have a lot to do with why individuals get sick in the winter.

Cold,

Viruses

It is suggested that there is a cascade effect that happens in the winter, and it breaks down like this:

- Dry winter air causes virus droplets to break up into smaller pieces—allowing them to linger in the air longer.
- Our bodies work harder to hold in heat, and it can lower

our ability to fight off said viruses hanging out in the air.

 Naturally, people spend more time indoors and in enclosed spaces because it is cold and wet outside, allowing us to contact more people and a higher concentration of viruses in the air.

And finally, as we spend more

time indoors, we develop vitamin deficiencies that lower our defense mechanisms.

DH MY!

Typically, viruses enter through the nose, mouth, or eyes. The virus can spread through droplets when someone sneezes, coughs, or talks. "The common cold is a viral infection of your nose and throat (upper respiratory tract). It is usually harmless, although it might not feel that way. Many types of viruses can cause a common cold.

"Healthy adults can expect to have two or three colds each year. Infants and young children may have even more frequent colds," according to the Mayo Clinic. However, there are several tips to keep in mind when preparing for the winter season. Practicing these habits can help you and your family avoid getting sick.

### VITAMIN D

In the short days of winter, without much sunlight, we may run low on Vitamin D, which helps power the body's immune system. According to Healthline, "Reports indicate that many Americans fall short of their daily vitamin D requirements. Low levels in vitamin D may lead to symptoms such as poor bone growth, cardiovascular problems, and a weak immune system". Aside from its vital role in supporting immune health, it is important to note the other essential benefits of vitamin D, including reducing depression, boosting weight loss, promoting healthy bones, supporting brain and nervous systems, lung function, and cardiovascular health.

There are several ways we can obtain more vitamin D. One is by going outside and getting enough sun. The vitamin is produced through the skin from the sunlight. Another way of obtaining the vitamin includes eating certain types of food, including salmon, sardine, egg yolk, shrimp, milk, cereal, yogurt, and orange juice. Lastly, you can get vitamin D also by purchasing vitamin D supplements at your local vitamin store.

### STAY WARM

Secondly, staying warm and dry might sound like common sense. However, during cold weather, some of our natural defenses change. For example, "when we breathe in cold air, the blood vessels in our nose may constrict to stop us from losing heat. This may prevent white blood cells (the warriors that fight germs) from reaching our mucus membranes and killing any viruses that we inhale, allowing them to slip past our defenses unnoticed." As it gets cooler outside, and as many businesses are operating outdoors, it is important to dress correctly. Begin with layering your clothing with fabrics such as cotton or wool, and keep adding or taking away layers to keep you comfortably warm.

### GOOD HYGIENE

Anytime you walk into a public place, you are breathing in a fine mist of other people's coughs and sneezes—which can hang around in the air for days. In addition, many viruses can live on your hands and cause you to catch a cold.

It is essential to practice good hygiene. Face masks are now a common precaution to help



stop you from breathing in the germs, but you must use them along with washing your hands regularly for 20 seconds with soap and water. Because viruses can enter the body through these areas, be careful not to touch your eyes, nose, or mouth

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### Continued from page 9

with unwashed hands. Finally, and most importantly, stay away from sick people because they could be shedding viruses. "It also spreads by hand-to-hand contact with someone who has a cold or by sharing contaminated objects, such as eating utensils, towels, toys, or telephones. If you touch your eyes, nose or mouth after such contact, you're likely to catch a cold," according to Mayo Clinic.

### STAY ACTIVE

Exercise helps your body stay healthy and strong. Staying active can help reduce stress, reduce inflammation, and boost white blood cells. There are many other benefits of exercising as well.

A healthy lifestyle does not only include your physical but also your mental health. Stress is linked to illness. "Stress that's left unchecked can contribute to many health problems, such as high blood pressure, heart disease, obesity, and diabetes," according to Mayo Clinic. Practicing de-stressors such as meditation, yoga, taking a walk, or reading can help improve your health.

### MORE SLEEP

A lack of sleep can also contribute to someone beginning to feel ill. Sleep helps to repair the body after a long day. It is recommended for adults to sleep about 7 hours a day.

"Healthy adult participants who slept a minimum of eight hours each night over two weeks showed greater resistance to the virus. Conversely, those who slept seven hours or less each night were about three percent more likely to develop the virus after exposure," according to Healthline.

Other health conditions attributed to a lack of sleep are high blood pressure, diabetes, and obesity. Individuals can improve their sleeping habits by committing to a regular sleep schedule, getting natural light, doing physical activity, avoid being on your phone, and limiting food or drinks before bed.

### COVID-19

We need to be aware of people getting regular colds or cases of the flu this winter. Nevertheless, now, we also have to be mindful of COVID-19. In general, the precautions people need to take with COVID-19 are similar to colds. Many of these practices that have been mentioned can also help prevent you from getting COVID-19, such as washing your hands, taking immune-boosting vitamins, and practicing a healthy lifestyle.

Still, since COVID-19 is a highly contagious virus, it is essential to follow any preventive measures the health experts recommend. You can find more information on preventing COVID 19 infection on the CDC https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html.

Being mindful and practicing these habits daily can dramatically decrease your chances of getting sick. But, of course, even if you practice these healthy habits, you still might catch a cold, so it is essential to continue getting your yearly checkups and communicating with your doctor on how you are feeling or improving your immune and overall health.

### Sources:

Healthline: "The Benefits of Vitamin D" https://www.healthline.com/health/ food-nutrition/benefits-vitamin-d Healthline: "The Secrets to Never Getting Sick" https://www.healthline.com/health/coldflu/cold-flu-secrets Hexaware: "How to Avoid Getting Sick this Winter' https://hemaware.org/mind-body/howavoid-getting-sick-winter Centers of Disease Control: How Does Sleep Affect Your Health? https://www.cdc.gov/bloodpressure/ sleep.htm Mayo Clinic: Common Cold https://www.mayoclinic.org/diseases-conditions/common-cold/symptoms-causes/syc-20351605 BBC Future: The real reason germs spread in the winter https://www.bbc.com/future/article/20151016-the-real-reason-germsspread-in-the-winter

### LETS TALK ABOUT IT! 2021 WEBINAR SERIES Feeling isolated? Ready to feel connected? Join us! Brothers Healthcare's very own Veronica Diaz, LCSW hosts a casual video chat series! **Topics include but not limited to:** Dates for 2021: - Goal Setting 1/13 7/14 8/11 - Mental Illness in Children 2/10 - Healthy Nutrition 3/10 9/8 4/14 10/13 - Managing Sibling Dynamics 11/10 - 504 and IEP plans 5/12 12/8 - Signs and Symptoms of Drug Addiction 6/9 All meetings take place at 4:30 PM & 6:30 PM

To register: https://forms.gle/Pv5vidFC1FogGrgL9

## DO WE REALLY NEED TO TEACH AN OLD DOG A New Trick?

We have all heard the saying, "you can't teach an old dog a new trick." Is that really a fact, or is it a long-standing myth, so to speak? When it comes to the treatment of Hemophiliacs, there are a plethora of old dogs (so to speak) that are not interested in any "new treatments."

 THERE ARE MANY REASONS WHY A PERSON MAY OR MAY NOT BELIEVE IN OR WANT TO PARTICIPATE IN THE NEWEST AND SUPPOSED BEST TREATMENTS."

Since we're talking a bit about euphemisms, here's one that has been employed throughout my experience as a Hemophiliac's father, "if it isn't broken, don't fix it." Of course, these thoughts are my own and do not reflect any facts or data; however, they are based on my almost thirty years of working in the Bleeding Disorders community and being the father of a 26-year-old severe factor IX patient. Over the time of my career, I have had many friends and acquaintances who are Hemophiliacs; many of these gentlemen, are of course, middle-aged and older. I have seen with my own eyes and through discussion with many of these fellows that they are not interested in the newest, latest,

or greatest treatment. This is especially true when they have already found something that is safe and works for them. Of course, choosing a treatment that works is a primary interest, but safety based on many of their first-hand experiences is paramount. There is a fear that lingers like a dark cloud over the heads of these older Hemophiliacs. A significant fear that these men and many of my friends experience, and I would say, for a good reason.

An older Hemophiliac patient's fear and apparent reluctance to willingly change his treatment regimen comes from what I can only describe as a travesty. A possibly avoidable turn of events in the late 1970s and early 1980s that left many in the older Hemophilia community infected with HIV and Hepatitis C.

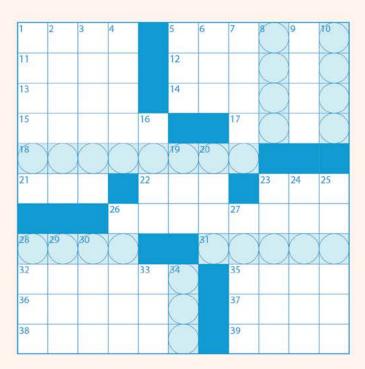
### HOW COULD THIS HAPPEN; why was this allowed to take place?

Many of those questions are answered differently depending on who you ask and how those people were affected. Many of my friends with HIV and HEP C were subject to these infections by using the latest treatment offered for their Hemophilia (at that time). This was around the time when factor concentrate products were becoming more prevalent. In the words of my close friend Rocko, "these factor products were a game-changer for us Hemos, they allowed us to

Continued on page 14



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
- Check out the \_\_\_\_\_ treated bleeds data with HEMLIBRA
- 31. Number of dosing options HEMLIBRA offers

<sup>†</sup>Number of people with hemophilia A treated as of February 2021.

- 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
- 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<sup>†</sup>

### SOLUTIONS

Across: 1. cask, 5. cksens, 11, Aden, 12. partsh, 13. tore, 14. used to, 15. cruel, 17. nest, 13. tore, 14. used to, 15. cruel, 23. MCs, 26. passport, 28. zero, 31. three, 32. spelet, 35. Otoe, 36. atrose, 37. three, 32. spelet, 26. cruel, 56. polosr, 27. three, 32. spelet, 29. steels, 26. polosr, 27. three, 9. MST, 10. shot, 29. steels, 26. polosr, 27. three, 28. seel, 29. Eyre, 25. steels, 26. polosr, 27. three, 28. seel, 29. Eyre, 25. steels, 33. ESE, 34. ten

### 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.** 



### **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: stomach (abdomen)
  - confusion weakness
    - - or back pain \_

\_

- swelling of arms and legs
  yellowing of skin and eyes
- 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: cough up blood
  feel faint
  - swelling in arms or legs
  - pain or redness in your
  - arms or legs shortness of breath
- numbness in your face \_
- chest pain or tightness fast heart rate
- eye pain or swelling
  trouble seeing

headache

### 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
- ose hEmilipite exactly as prescribed by your neutricate 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.

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treat on-demand and that was not possible before." Previous to making use of factor concentrates, patients could spend days in the hospital connected to an intervenes infusion of what was called Cryo-Precipitate. *Cryoprecipitate Antihemophilic Factor, also called cryo, is a portion of plasma, the liquid part of our blood. Cryo is rich in clotting factors, which are proteins that can reduce blood loss by helping to slow or stop bleeding.* 

### UNFORTUNATELY, THESE "GLORY Days" were short-lived for Many hemophiliacs

As you can imagine, the introduction of factor concentrates for Hemophiliacs across the country was a huge deal. Finally, a less time-consuming, more convenient, and readily available treatment. It was like a dream and was very quickly embraced and utilized.

One must understand that these wonder drugs (factor concentrates) were a godsend for people with hemophilia, but they brought a wave of devastation with them. As I mentioned, they imparted HIV and HEP C to a large population of the community. This came about through the collection of plasma, the main component of these new factor concentrates. Blood banks and blood donation centers would collect blood from anywhere possible. That meant that while it was not limited too, it largely included the homeless, derelict, and many times intravenous drug user population. At that time, the collection centers

had no way to track nor screen persons who would give their blood to collect a few dollars. Once the blood donations were collected across the country, the plasma was then separated from the whole blood and pooled. In effect, a massive mixture of plasma is collected from literally thousands of unknown persons, and more importantly, from people with unknown or undisclosed health issues or diagnoses. This was how the HIV and HEP C epidemic infiltrated the new factor concentrates and subsequently the Hemophilia/Bleeding Disorders community. Because of the mass destruction that ultimately came to the community's health, many persons receiving treatment for their Hemophilia have been fearful and skeptical of the next "big" thing and the possibility of unknown infections or hardships that could unknowingly arise.

The whole reason behind this writing is to illustrate how and

why, especially for those older persons in our Hemophilia community, might be reluctant to try new treatments, maybe stay away from or even avoid these so-called "state-of-the-art" treatments for their bleeding disorders. Perhaps some of them have had enough innovation. Maybe they do not want to risk even more harm or an added diagnosis to their seemingly long list of illnesses. Perhaps, this is a fine example of trying to teach a resistant "old dog a new trick." I prefer, "if it isn't broken, don't fix it." Whatever the case may be, I personally think that until we walk a mile in anyone else's shoes, we do not make judgments or try and persuade others to do what we feel is best for them as individuals. There are many reasons why a person may or may not believe in or want to participate in the newest and supposed best treatments. We have a long history of outstanding accomplishments in our

Bleeding Disorders community. Still, we also have some tragedy and pain that is difficult to recover from, PTSD, if you will. We should always recognize that we, whether affected by a bleeding disorder or something else, should be left to make our own informed decisions about our care and health treatments. We should also respect the reasons behind those decisions. There is always more than meets the eye, and I can see and appreciate why our older Hemo's, as they so lovingly refer to themselves, see things the way they do. I can fully understand why many times, it really is not about teaching an old dog a new trick, but more about why that dog refuses the trick. Be more understanding, be more conscientious about others and the walk they are on.

American Red Cross. What is Cryoprecipitate? 2021. Accessed 6 September 2021. https://www. redcrossblood.org/donate-blood/ dlp/cryoprecipitate.html.





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