



DATELINE

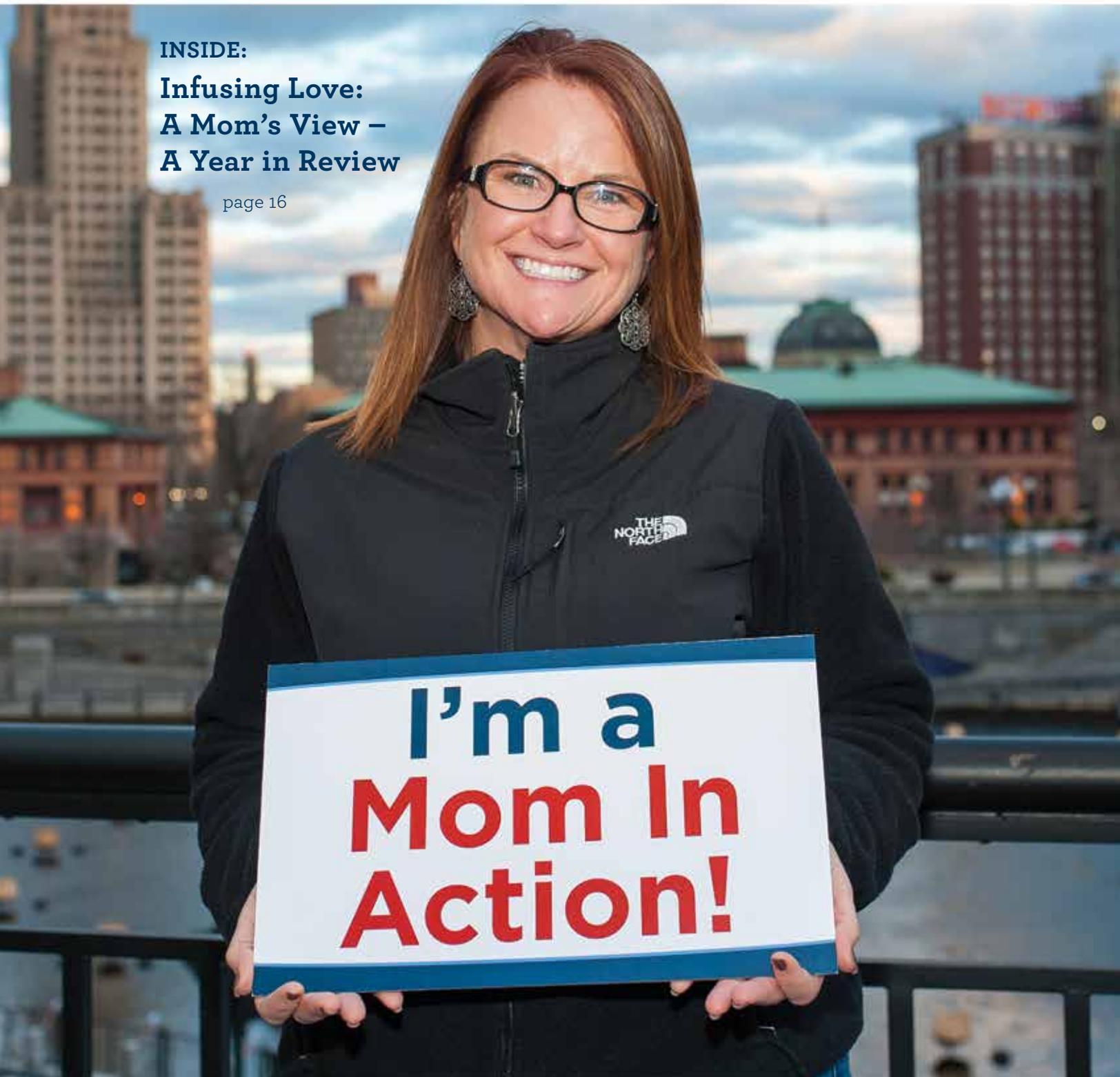
F E D E R A T I O N

Issue 55 | Volume 17 | Winter 2017

INSIDE:

**Infusing Love:
A Mom's View –
A Year in Review**

page 16





SISTERHOOD APP

You asked, we listened

HFA knows how critical an early diagnosis is for treatment and quality of life for women and girls with a bleeding disorder.

That is why we created Sisterhood, a mobile app designed for women to track menstrual and non-menstrual bleeds and symptoms.

Information logged by the user is secure and accessible only to the user. The user can have the app email that secure information to themselves to then share with their medical services provider.

New features include:

Recording details on product strength. Users may now note the strength of menstrual products used when logging menstrual bleeding by choosing the detailed data entry in the preferences tab.

More accurate blood loss score (PBAC score) for providers. Having more detailed information allows providers to more accurately assess blood loss that assists in diagnosis.

Ability to add a photo. • Spanish language option.

Other features of the app include:

Symptom logging/tracking. • The ability to record and track treatments used.

Reminder alerts for periods and treatments. • A place to log and rate joint and/or muscle pain.

Space to jot additional notes. • A wealth of information on bleeding disorders and a variety of topics pertaining to women and bleeding disorders.



It's free and easy to use. Download it for FREE!





Assisting and advocating for the bleeding disorders community since 1994.

Issue 55 | Volume 17 | Winter 2017

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Tracy Cleghorn

President & CEO

Kimberly Haugstad, MBA

PRODUCTION TEAM

Editor

Kyle McKendall

Copy Editor

Kit Salisbury

Design & Layout

Kristin Mitchell Design, Inc.

CONTRIBUTORS

Michael Bishop, Staff

Martha Boria, Staff

Meredith Clark, Staff

Mike Hargett

Carrie Koenig, Staff

Jill Packard

Christa Parra

Donna Shaw

Sarah Shinkman, Staff

Eric Weinberg

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820 First Street NE, Suite 720

Washington, DC 20002

800.230.9797

info@hemophiliafed.org

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Dear Reader,

When I wrote my contribution to the *Infusing Love: A Mom's View* blog last June, I focused on the emotions I was feeling about my son Nick finishing middle school and preparing to enter high school. I couldn't stop thinking about how fast time seems to pass; I had such vivid memories of putting him on the bus to kindergarten for the first time. It filled my heart with joy to think about the young man he is becoming and made me even happier to have a platform like *Infusing Love* to share our story. Over the years, I've enjoyed immensely reading stories from moms across the country and found great value in the act of sharing those personal narratives. I hope you'll take time to read the mom's blog 2017 year in review (pp. 16-17) – it's hard not to smile when reading these posts.

Throughout the remaining pages of this issue, you'll find personal stories from several other community members. Christa Parra details her experience of growing up as a "symptomatic carrier" and the eventual diagnosis of hemophilia she received later in life (p. 18). Never giving up is the core message of Mike Hargett's story in which he shares his experience of living with hemophilia while undergoing heart and kidney transplants (pg. 5). We're happy to see that he is doing well and recovering! Pain is a topic that's all too familiar, but I particularly enjoyed reading Michael Bishop's take on growing up with severe hemophilia B with an anaphylactic allergy to factor IX products (pg.30). While he certainly isn't dismissive of the pain people experience, having had his fair share of it, his outlook on how to live one's life is inspiring.

I understand how sharing our experience of living with a bleeding disorder can be intimidating at times and I certainly appreciate the efforts of these individuals in contributing to

Dateline Federation. Thank you, your contributions have a profound impact on bleeding disorder community members across the country.

In 2017, as in years past, HFA awarded \$10,000 in educational scholarships to community members who are pursuing higher education. I hope you'll turn to page 26 to see who this year's recipients are and read more about their educational goals and aspirations.

At the beginning of each New Year, it's customary to take time to reflect on your own accomplishments of the past year. At this time, I'd like you to reflect on the work we're doing together here at HFA as well. We have so much in store for the year ahead, including our annual Symposium being held in Cleveland, OH in April. I hope strengthening your connections with HFA made it onto your list of goals for 2018. We would love to have you attend one or more of our events, contribute to *Dateline*, or share a personal story on one of our blogs. At this time next year, we'll again be doing a 2018 year in review and we'd love to be able to include you. Just like with my experience watching Nick grow up, the years seem to be going by faster and faster, so don't hesitate to jump in! Decide how you want to make an impact in 2018 and let HFA be a part of your plan!

Warm regards,

Tracy L. Cleghorn

Tracy Cleghorn
Board Chair



Connect with us
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at HFA.

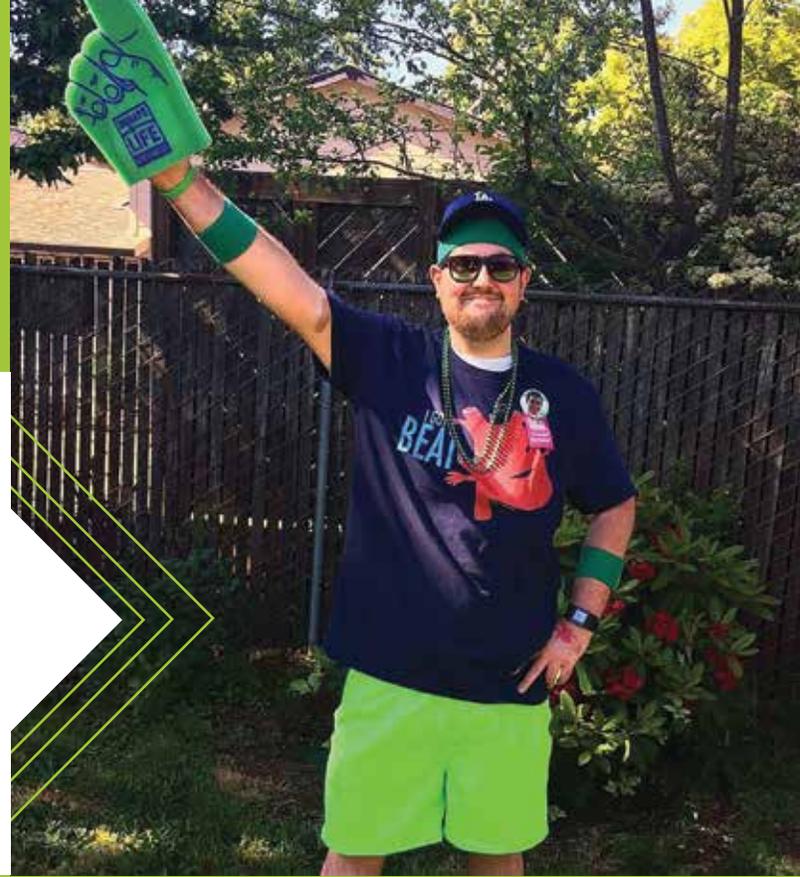


Mighty Mike

By Mike Hargett

“It’s hard to beat
a person who
NEVER GIVES UP.”

– Babe Ruth



When I was born, I broke my mom’s tailbone. Two days later the nurse taking care of me noticed that something wasn’t quite right, and kept me overnight for observation. As it turns out, I had incurred a massive subdural hematoma (a pool of blood between the brain and its outermost covering) during my birth that required surgery, to stop the bleeding and potentially-fatal swelling. They knew right then that I was a bleeder. Over the next two decades I experienced many hospital stays, medical treatments, and emergency room visits. In 1989, I tested positive for the antibodies for hepatitis C, contracted through tainted blood infusions that I received to treat my hemophilia, but it wasn’t until 1998 that I was actually diagnosed with the disease. I started calling Oregon Health &



Sciences University (OHSU) my “home away from home,” and I figure I basically funded their new aerial tram with all my medical bills over the years!

In 2005, my senior year of high school, I was diagnosed with dilated cardiomyopathy. My heart was so sick that I wasn’t able to even walk from one class to another. Even after being thrown this curveball I still graduated on time and was elected to the National Honor Society. Often, I tell people that, despite my heart condition and bleeding disorder being a major part of my life, those things don’t define me. I define them and how they fit in my life.

Over the following eight years those challenges took a toll on me. I often felt like the only thing I could control was my eating and I comforted myself with food. Paired with my lack of mobility, I gained a staggering 175 pounds. My ejection fraction (the measurement of the percentage of blood leaving your heart each time it contracts) kept decreasing, and the need for a heart transplant became critical. Finding a doctor to agree to do a transplant on a hemophiliac was a whole task in itself. First, I had to get treated and cleared for hepatitis C. Then it took going to five different facilities before I found a doctor who would agree to do this high risk heart surgery. I also needed to have a BMI (body-mass index) of 35, which would require a 200-pound weight loss. That took a little over two years. In



addition to those challenges, Dr. Michelle Kittleson and her amazing team at Cedars-Sinai had to provide three months of special training for their entire staff just for me to be able to do the surgery.

On May 9, 2016, I received the gift of my new heart: something I saw as extra borrowed time. This was my “encore,” and it was just beginning. Almost immediately after the transplant, my kidneys took a bruising because of the immunosuppressive medications I was on, and they started to fail. My creatinine sky-rocketed to almost 13, when a normal range is .6 - 1.5. I was on dialysis for a few days, which got my numbers under control, and that kept my kidneys happy... for a while. When I returned home they failed again, so now a kidney transplant was next on the list. I told myself I was just going to keep doing transplants, and become the bionic man: an idea I found pretty cool, actually. I started kidney dialysis in March 2017: three days a week, eight hours at a stretch. Happily, a living donor match was found and my transplant coordinator told me that in the

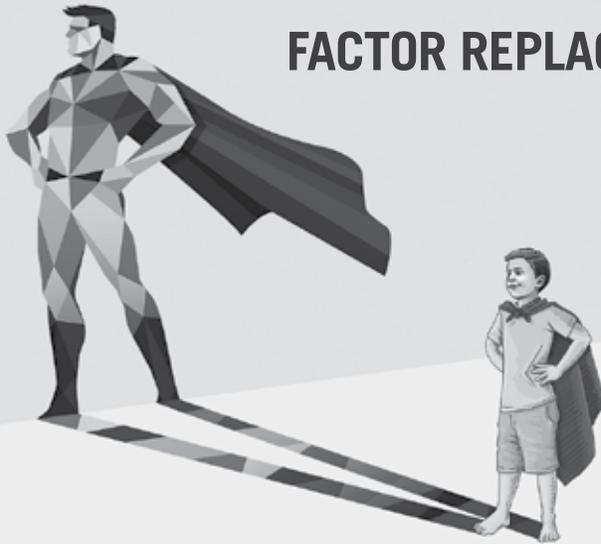
10 years she’s been doing her job she had never seen a closer match. Of course, the best benefit of such a close match is that the risk of organ rejection is low.

I received my second transplant on October 31, 2017 and I’m finally able to pee again! It’s the small things in the life that make a huge difference, and I’ll never take peeing for granted ever again, you can count on that! So, I’m the first double transplant recipient with hemophilia in the United States! A great friend and mentor of mine once told me that you never want to be the first or the last person to do anything. In this case I didn’t have a choice, but it’s still pretty cool to be a “first.”

Finally, it may seem obvious, but I am blessed for my selfless donors. I keep them in my daily thoughts and prayers; I hope you will, too. I wouldn’t be here to enjoy my next chapter if it wasn’t for them.

Thank you from the bottom of my (new) heart! ■■

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.¹ With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.^{2,3}

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 60 years.

Stay empowered by the possibilities.

References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. 2. Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia*. 2010;16(suppl 3):7-12. 3. King MW. Introduction to blood coagulation. <http://themedicalbiochemistrypage.org/blood-coagulation.php>. Last modified January 2, 2017. Accessed November 21, 2016.

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www.ADYNOVATE.com


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S32930 06/17



Young Adults: We've Got You Covered!

By Sarah Shinkman, Staff

Did you know that HFA has tons of resources for young adults ages 18-30? Whether you are working, studying, raising kids, or a combination of these things, we have tools to support you whenever and wherever you are.



HANGOUTS AND WEBINARS:

Since 2014, we've recorded 14 Google Hangouts and webinars for young adults with bleeding disorders on topics ranging from advocacy, relationships, transitioning to adulthood, financial management, insurance, and more. Watch the recordings on HFA's YouTube channel or website (www.hemophiliafed.org/programs/youngadults).



PODCASTS:

Our podcast series features seven episodes on health and wellness for young adults, including topics like managing stress, finding and maintaining motivation to stay fit, healthy eating on a tight budget, and more. Podcast episodes are available on iTunes and Google Play, search "HFA."



TOOLKITS:

Need advice on managing your bleeding disorder when you go to college? Starting a new job? Look no further than our "Off to College" and "Employment Issues" toolkits. Find these, and others, in our Resource Library at www.hemophiliafed.org.



IN-PERSON OPPORTUNITIES:

In October 2017, we hosted our inaugural Young Adult Advocacy Summit. Fifteen young adults from across the country participated in the four-day event at our office in Washington, DC. Attendees received trainings on state and federal policy, advocacy, coalition building, communications, and health insurance; met with 19 Congressional Offices; visited the Capitol and national monuments; and discussed issues facing young adults with bleeding disorders. Participants gained a deeper understanding of personal and legislative advocacy, developed ideas for engagement after the Summit, and formed lifelong friendships.

Highlights of the Summit included the policy update provided by our Policy and Government Relations Team and the opportunity to discuss current legislation with congressional office staff and representatives on Capitol Hill. One participant shared, "Learning [about] different bills allowed me to point out issues that affect everyone in the bleeding disorder community. Our voices mattered, and I believe we were heard. We are overcoming fears and becoming better leaders every day."

Symposium also offers opportunities for networking and education. When you register, select the Young Adults option to receive more information on ways to engage with your peers in Cleveland.

Looking for resources or opportunities not listed? Tell us what you want! Submit your ideas and questions to s.shinkman@hemophiliafed.org. ■■



Just B Happy

“When I manage my bleeds with IXINITY,
it allows me to do more and just be myself.

—Marcus has hemophilia B and uses IXINITY

See why Marcus switched to IXINITY at JustBIXperiences.com

This information is based on Marcus' experience. Different patients may have different results. Talk to your doctor about whether IXINITY® may be right for you.

INDICATIONS AND IMPORTANT SAFETY INFORMATION

What is IXINITY®?

IXINITY [coagulation factor IX (recombinant)] is a medicine used to replace clotting factor (factor IX) that is missing in adults and children at least 12 years of age with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY to control and prevent bleeding episodes or when you have surgery.

IXINITY is not indicated for induction of immune tolerance in patients with hemophilia B.

IMPORTANT SAFETY INFORMATION for IXINITY®

- You should not use IXINITY if you are allergic to hamsters or any ingredients in IXINITY.
- You should tell your healthcare provider if you have or have had medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.
- You can experience an allergic reaction to IXINITY. Contact your healthcare provider or get emergency treatment right away if you develop a rash or hives, itching, tightness of the throat, chest pain, or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

- Your body may form inhibitors to IXINITY. An inhibitor is part of the body's defense system. If you develop inhibitors, it may prevent IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to IXINITY.
- If you have risk factors for developing blood clots, the use of IXINITY may increase the risk of abnormal blood clots.
- Call your healthcare provider right away about any side effects that bother you or do not go away, or if your bleeding does not stop after taking IXINITY.
- The most common side effect that was reported with IXINITY during clinical trials was headache.
- These are not all the side effects possible with IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

You are encouraged to report side effects of prescription drugs to the Food and Drug Administration. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see accompanying brief summary of Prescribing Information on next page.



IXINITY® [coagulation factor IX (recombinant)]

Brief Summary for the Patient

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.IXINITY.com.

Please read this Patient Information carefully before using IXINITY. This brief summary does not take the place of talking with your healthcare provider, and it does not include all of the important information about IXINITY.

What is IXINITY?

IXINITY is a medicine used to replace clotting factor (factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY when you have surgery.

IXINITY is not indicated for induction of immune tolerance in patients with hemophilia B.

Who should not use IXINITY?

You should not use IXINITY if you:

- Are allergic to hamsters
- Are allergic to any ingredients in IXINITY

Tell your healthcare provider if you are pregnant or breastfeeding because IXINITY may not be right for you.

What should I tell my healthcare provider before using IXINITY?

You should tell your healthcare provider if you:

- Have or have had any medical problems
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies
- Have any allergies, including allergies to hamsters
- Are breastfeeding. It is not known if IXINITY passes into your milk and if it can harm your baby
- Are pregnant or planning to become pregnant. It is not known if IXINITY may harm your baby
- Have been told that you have inhibitors to factor IX (because IXINITY may not work for you)

How should I infuse IXINITY?

IXINITY is given directly into the bloodstream. IXINITY should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their IXINITY by themselves or with the help of a family member.

See the step-by-step instructions for infusing in the complete patient labeling.

Your healthcare provider will tell you how much IXINITY to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting IXINITY to be sure that your blood level of factor IX is high enough to stop the bleeding. Call your healthcare provider right away if your bleeding does not stop after taking IXINITY.

What are the possible side effects of IXINITY?

Allergic reactions may occur with IXINITY. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms:

- Rash
- Hives
- Itching
- Tightness of the throat
- Chest pain or tightness
- Difficulty breathing

- Lightheadedness
- Dizziness
- Nausea
- Fainting

Tell your healthcare provider about any side effect that bothers you or does not go away.

The most common side effect of IXINITY in clinical trials was headache.

These are not all of the possible side effects of IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

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

How should I store IXINITY?

250 IU strength only; store at 2 to 8°C (36 to 46°F). Do not freeze.

500, 1000, 1500, 2000 and 3000 IU strengths; store at 2 to 25°C (36 to 77°F). Do not freeze.

Do not use IXINITY after the expiration date printed on the label. Throw away any unused IXINITY and diluents after it reaches this date.

Reconstituted product (after mixing dry product with Sterile Water for Injection) must be used within 3 hours and cannot be stored or refrigerated. Discard any IXINITY left in the vial at the end of your infusion.

After reconstitution of the lyophilized powder, all dosage strengths should yield a clear, colorless solution without visible particles. Discard if visible particulate matter or discoloration is observed.

What else should I know about IXINITY?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's immune system. If you form inhibitors, it may stop IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests to check for the development of inhibitors to factor IX. Consult your doctor promptly if bleeding is not controlled with IXINITY as expected.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use IXINITY for a condition for which it is not prescribed. Do not share IXINITY with other people, even if they have the same symptoms as you.

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.



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CM-FIX-0078

Choosing Healthy Foods on a Budget — Being Informed at the Grocery Store

By Meredith Clark, Staff



Eating right and maintaining a healthy weight are important for our health and wellness. Not only does proper nutrition give your body the nutrients it needs to function at its best, but staying at a healthy weight takes unnecessary stress and pressure off our joints and muscles. Additionally, a healthy eating lifestyle affects other aspects of our lives—from self-confidence and self-love to our social health.

Think back on the last time you walked into a grocery store and how bombarded you felt by the colorful displays all begging for your attention, the shelves of seemingly-identical products, and the information overload offered on the packaging. There are so many factors you have to consider when choosing what to buy, such as cost, nutritional value, flavor, cooking and preparation time—it can seem overwhelming. To further complicate our decision-making, nutritional claims on packaging and product advertisements are all over the place. To help us make informed decisions at the grocery store, we sat down with Kathryn Clark, a registered dietician and guest speaker on HFA's Young Adults Podcast Series.



HFA: What advice do you have for young adults for navigating the grocery aisles and making healthy food shopping choices?

Kathryn: This is the number one message for anyone shopping on a budget: buy what is in season. Also, if you can, buy locally grown fruits and vegetables. They will tend to be fresher and have more vitamins because they haven't been sitting around so long getting to market. The cost, however, may be a bit higher when you buy locally, as smaller farmers can't spread their expenses over huge yields like agribusinesses can.

Check out the specials in your grocery store and plan your menu around those foods. Another possibility, which will save money down the road, is to buy a little extra of what is on sale for your pantry. Of course, this strategy won't work for perishable items like fresh vegetables and fruit. Another good reason to plan meals ahead of time is so you see what you already have at home which needs to be eaten, avoiding wasting food.

Buy store brands. In many cases, they are just as good as a commercial label and much less expensive. We buy the store brand of shredded wheat, which tastes just like Nabisco's. And, sure enough, the ingredients are the same. On the side of the box the ingredients are listed in order of weight. In shredded wheat, for example, there is only 100% whole grain wheat: very simple compared to most products!

Every now and then you may want to buy prepared foods, but if you really want to save money, cook at home. You can halve your grocery bills and you will have healthier meals with less salt and fat.

HFA: What information should you pay attention to when choosing between products and brands?

Kathryn: The Food and Drug Administration (FDA) requires and monitors food labels on packaging. The label, called Nutrition Facts, will tell you the serving size, calories per serving, and the number of servings in that package. It will also give you the information per serving including total fat (and, of that, how much is from saturated fats and trans fats), cholesterol, sodium, potassium, carbohydrate (and of that, how much is of it is fiber and how much is sugar), and protein. Next to those numbers are the percentages you will get of that nutrient, based on a 2,000 calorie diet.

HFA: Is it safe to trust the information given on the front of the package?

Kathryn: I would not trust the unregulated claims on the front of labels, unless they are specific claims, like 100% whole grain, certified organic or GMO-free. Of the vaguer claims, like cage-free, free-range and all natural, you will need to dig further. For example, "all natural" doesn't mean anything since no governmental agency regulates the term. I looked at a package of deli meats which claimed this, and it said simply it was "uncured ham," just meaning no nitrates or nitrites. On the label for Kashi cereal, it says "7 whole grain nuggets." To check on that claim, you need to look at the ingredient label which reads: "whole: oats, wheat, rye, brown rice, triticale, barley, buckwheat." Those are the seven grains. They also add ground up sesame seeds into sesame flour. Whole grains have all three parts of the grain; the bran, endosperm and germ. Wheat flour, however, has only the endosperm, so it is not considered whole grain.

HFA: There are so many other claims on packaging and advertisements being thrown around these days. Could you explain the meaning behind some of them?

Kathryn: There are many terms that don't have specific definitions, are not regulated and therefore, can be misleading. These are a few of the terms you see often.

Organic—Unlike "natural", organic does have a specific definition. If meat is labeled organic, it means the animal was not fed antibiotics or given hormones to make it grow bigger and faster. It was also not fed food with pesticides, so it grazed on fields which were free from pesticides. Organic fruits and vegetables, coffee, grains, and so on, were grown on land free from chemical pesticides and fertilizers and were not sprayed with chemical pesticides.

Probiotic - This is good bacteria, which is the same as, or very similar to, bacteria found in our digestive systems. Examples are yogurt, kefir and some fermented foods such as sauerkraut and kimchi. On the yogurt label, it will say "contains live, active cultures." The benefits of probiotics are to prevent bowel problems such as constipation or diarrhea.

Omega 3 fatty acid - Food packages are touting these fats because they have health benefits that promote immunity,



help maintain good cholesterol and triglyceride levels and are good for the heart. Omega 3s are fatty acid chains found in certain foods and not produced in the body. Excellent sources are fish (salmon, tuna, trout), walnuts and flaxseeds.

Antibiotic free—Products coming from animals that have not been treated with antibiotics. Often animals are given antibiotics prophylactically while living in tight quarters. When you are eating the meat of an animal that has been raised on antibiotics, you are unnecessarily dosing yourself with those antibiotics, and could build up a resistance to that drug.

Grass fed—This term refers to beef cattle that were not fattened up on grain before slaughter.

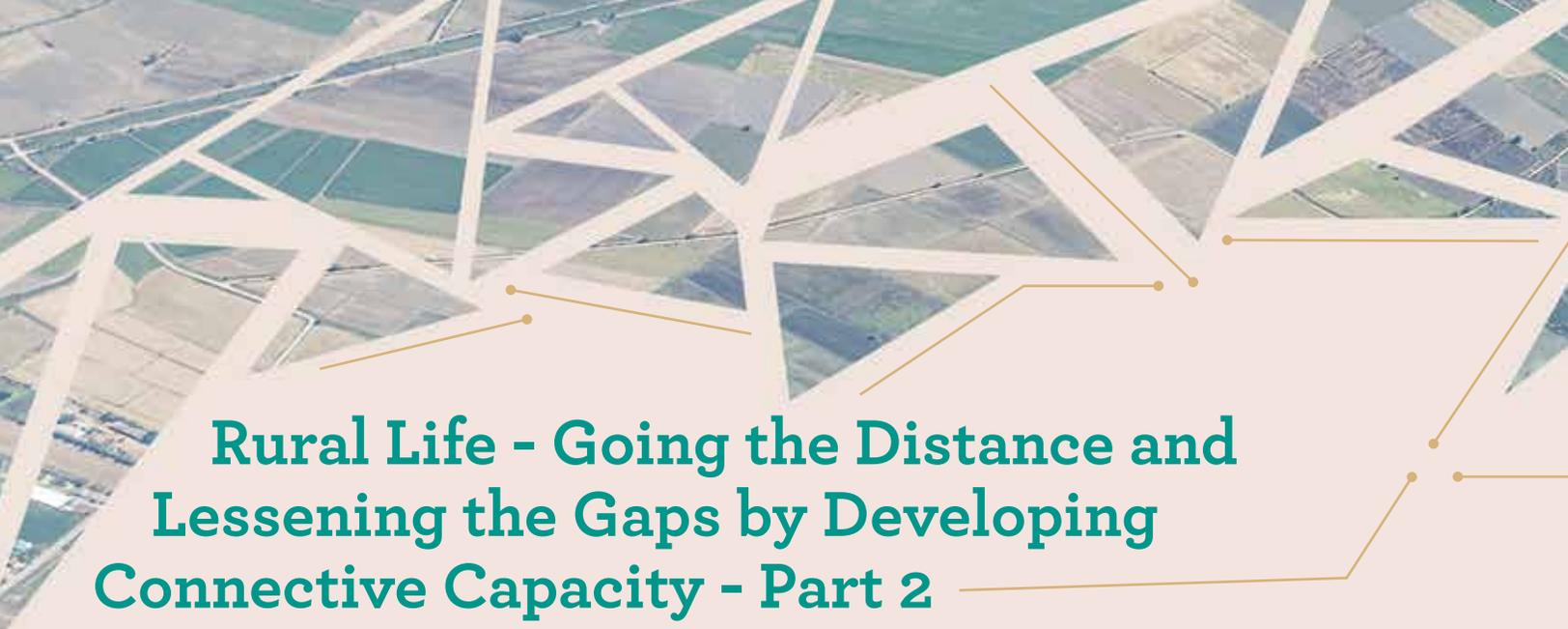
Certified humane—Food products have come from facilities that meet precise, objective standards for farm animal treatment, certified by Humane Farm Animal Care, an international nonprofit organization. You might see terms like free range and cage free often in relation to chickens and eggs, but those claims are not regulated.

HFA: What advice do you have for someone shopping on a tight budget?

Kathryn: First, keep in mind what you are striving for: the best food for the best price. So, the best diet is: a lot of fruits and vegetables (5-8 servings/day), whole grains, fatty fish (high in omega-3 fatty acids such as salmon), lean sources of other protein foods, such as meats, dairy foods, and beans.

Suggestions:

- Shop smart. Shop for items on sale and use sale coupons when you can. Buy in bulk if you plan on eating it all or can store it for future use.
- Always check to see what you have in the house before shopping.
- Plan your meals. Have a rough idea of what you will eat for the week.
- Remember, you don't have to eat meat every day. For supper, try a vegetarian option such as bean burritos, lentils and rice (Indian dal is delicious and spicy!), pasta with broccoli, or a cheese omelet with mushrooms. Soups are hearty and you can eat lots of those vegetable servings that way.
- Tuna fish salad can be stretched by adding cut-up grapes or diced celery.
- Have a dessert made with fruit, such as baked apples, strawberries with vanilla yogurt, or simply a bowl of fresh fruit. Dessert can include a dairy serving, such as custard or pudding, or, yes, ice cream occasionally, or sherbet.
- Look for and try new recipes.
- Avoid packaged foods for the most part. They are generally full of sodium and they are relatively expensive for the amount of nutrition you will get from them. ■ ■



Rural Life - Going the Distance and Lessening the Gaps by Developing Connective Capacity - Part 2

By Jill Packard

In the last issue of *Dateline*, we identified and discussed Connective Capacity as the foremost mechanism used to increase the overall health of a community.¹ In our case, Connective Capacity is the level to which an individual or organization is able to recognize, value, operationalize, and implement systems that ensure strong and positive communication flow between stakeholders. We went further to identify that there are unique challenges to living rurally and that we are especially vulnerable and challenged when communication degrades.

Much of what was discussed in the earlier article focused on what Hemophilia Treatment Centers (HTCs) could do to support Connective Capacity development. We discussed their role in maintaining a healthy community and went further to identify what HTCs could do to ensure community health. Going deeper, to *ensure long-term sustainability*, we must also bring attention to our nonprofit community and its role in developing our community's Connective Capacity.

This leads us to ask two important questions:

1. What are Member Organizations currently doing to influence and support an increase in our community's overall Connective Capacity?
2. Where there is attention on developing Connective Capacity, are we digging deep enough?

Of course, we don't technically know the answers to these questions. As a community, we've not done any official research on the topic and only a few organizations are starting to look

¹ There are many organizations that focus on intentional community design. Current organizations identify community and collective impact models as the outcome of their design. For more information about community building and collective impact consider checking out the Tamarack Institute.

at the impact of community connection. However, that said, doing a quick, observational survey of national, regional, and state-based Member Organizations, we can surmise quickly that we have much room to improve. Ranging from tangible to intangible opportunities for developing connectivity, let us dive in.

Supporting internet connectivity. According to the National Rural Health Association (NRHA) and the Federal Communications Commission,² "fifty-three percent of rural Americans lack access to 25 Mbps/3 Mbps of bandwidth, the benchmark for internet speed according to the Federal Communications Commission. Lack of high-speed internet access can be a hindrance to accessing information, representing another challenge rural Americans face." Increasingly, social media and the *internet of things* have increased our community's ability to connect. We know that our rural community members' lack of access to broadband directly impacts a community's ability to develop its Connectivity Capacity. *Advocating for rural broadband connectivity is a must!*

To increase connection, Member Organizations need to embrace local models. Author and community development leader Paul Born speaks regularly about the power of the small group to create change, asserting that there is a direct correlation between people's sense of community and their willingness to improve the conditions of those who live around them. With that, the NRHA states that people who live in rural areas have greater transportation difficulties, not only in reaching health care providers, often having to travel great distances to a doctor or hospital, but also connecting with a support network.

² <https://www.ruralhealthweb.org/about-nrha/about-rural-health-care>



We must help our community members identify their own inherent value and power, and support their growth

If we have the expectation that as a national community we are going to sustain, we must continue to grow and develop—we must embrace the small group in the local area as a valuable model of connection. In rural areas, embracing the small group means *meeting people where they are*, providing education and support where they can access it most easily, and helping them create connections where they are.

Embrace inclusion as an operative mechanism. Simply stated, seek out *others*. Reach those you would call the “underserved.” Find the people who are not connected because of language, gender, religious difference, or other perceived barriers that keeps them from engaging with the community at large. Address bias within communities. Pull the women in as close as possible! CREATE CONNECTION WHERE IT IS LACKING!

If you are a leader, create mechanisms that make this connection possible. If you are an affected person who feels excluded, ask your leadership to create opportunities for you to engage with the community at large that are respectful of your needs—and expect nothing less! If you are someone who believes in radical inclusion, speak up!

The National Council of Nonprofits believes that embracing diversity, inclusion, and equity as organizational values allows us to intentionally make space for positive outcomes to flourish. Working through models of inclusivity creates opportunity for better decision making, enhanced innovation,³ and connected systems. Take a look at how your organization is embracing diversity and create a discussion today!

Develop a growth mindset as part of organizational and community culture. If there is one single thing we can do as Member Organizations and as a community to enhance Connective Capacity it is this: we must help our community members identify their own inherent value and power, and support their growth. By facilitating a growth mindset, research says

³ <https://www.councilofnonprofits.org/tools-resources/why-diversity-inclusion-and-equity-matter-nonprofits>

that we will create a membership that feels more empowered, committed, collaborative, and innovative. This in turn has the potential to enhance Connective Capacity.

In closing, we must always remember that these issues are not specific to the bleeding disorders community, and challenges face us all. But, given that, we can and should recognize that we have a unique opportunity to demonstrate how a diverse group of people who are *bound by blood* can overcome those same challenges. We really do accomplish so much more together.

When we look closer at the bleeding disorders community, we can confirm that there are many other *central* stakeholder groups that are responsible for the connective capacity of our community. They are our affected member population, non-profit partners,⁴ industry partners,⁵ care providers,⁶ and our governmental representatives. While we are often challenged to see these parts as a whole, we depend on all of these entities for community health and community connectivity. If we are looking to create a truly sustainable and healthy community, able to weather volatile markets and changing political landscapes, we must focus on developing our overall capacity to connect with each other on as many levels as possible.

As a community, we must decide what we value, and learn to raise our expectations about the quality of our relationships. Our end goal should be *whole and healthy people who know and understand each other, always*.

If you or your organization has interest in being part of the movement to change bleeding disorders care, please share your ideas on HFA’s Research Portal or email CAWG@hemophiliafed.org. ■■

⁴ Some of our nonprofit community organizations are not transparent and do not appear to embrace nonprofit best practices. Please make sure to educate yourself about the nonprofits with whom you choose to share your resources.

⁵ Industry partners are those organizations that receive dollars from the sale of factor/prescription medication necessary for the treatment of bleeding disorders.

⁶ High-touch pharmacies overlap between the care provider category and the industry category.

Infusing Love: A Mom's View— A Year in Review

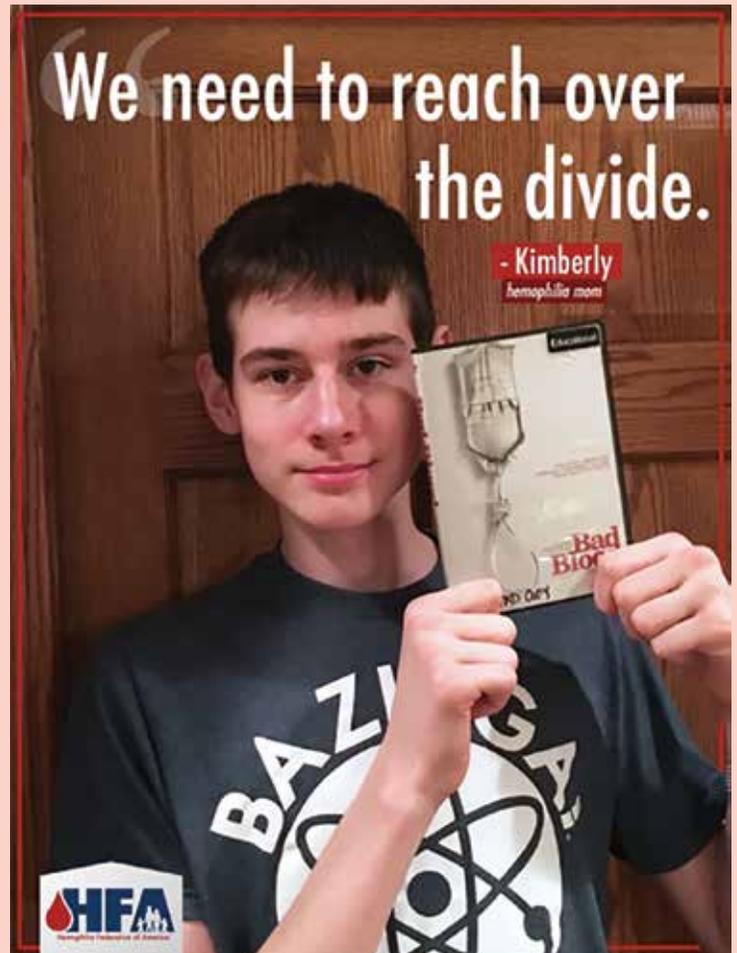
By Carrie Koenig, Staff

While being the parent of a child with a chronic illness can sometimes feel isolating, unforgiving, and, often, monumentally challenging, having a child with a bleeding disorder can amplify these feelings. Thankfully, we have a strong community full of support to sort through these emotions.

During the holidays, we try to squeeze as much love and appreciation we can into a small window of time. It's important to reflect on how grateful and proud we are to be a part of such a wonderful community of families, blood brothers, and blood sisters who provide us with such support. Take a peek at what some of our *Infusing Love: A Mom's View* bloggers have said about our community, our family, throughout 2017.

Kristi from Vermont:

"We are privileged to have access to the resources that make this [situation] manageable, and have a responsibility to share those resources with those who cannot."



Kimberly from Wisconsin:

"For a great many of our older guys who lived our history, they take the responsibility of educating our kids very seriously. I am humbled and honored that I can count on their help to give my child this knowledge and strength."

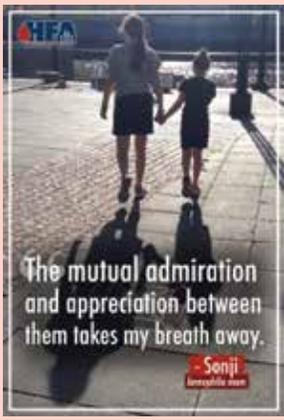


Martha from New York:

"The diagnosis of a bleeding disorder or a chronic illness can be devastating and impacts the whole family. Nevertheless, it doesn't matter where you come from, what chronic illness you have, or the obstacles you face, no dream is off limits for us in the United States."

Cazandra from New Mexico:

"[My son] was empowered. He was surrounded by other boys who dealt with many of the same issues and he realized he was not alone."



Kari from California:

"I just want to say: thank you, thank you, thank you to all the ladies from this community I've leaned on this last year. I'm forever grateful to have you in my life and can't wait to watch these relationships grow."



Emily from Minnesota:

"One of the largest takeaways I have received from the bleeding disorder community is that I am my child's best advocate. I know him best and I will fight tooth and nail for him."



Maryann from New Hampshire:

"Words on paper can't express how you shaped who I have become. 'Thank you' is not nearly enough."

Sonji from Colorado:

"These girls have been through so much, but they have been through it together. What might just have been a normal sisterly bond has been strengthened because of hemophilia."

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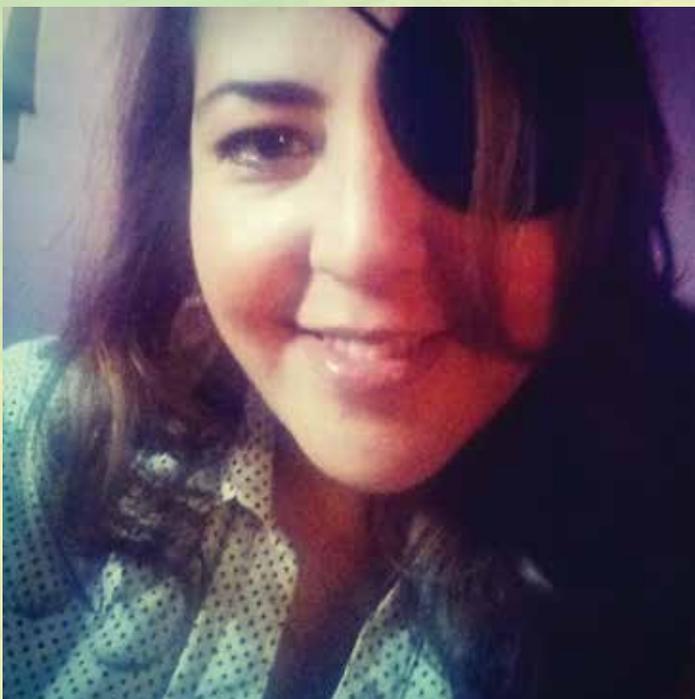
When You're Not “Just A Carrier”

By Christa Parra

The earliest memory I have of experiencing symptoms of a bleeding disorder was when I was five years old. I had a black eye that was swollen shut for about two weeks, followed by a bruise that lasted another month. The childhood bloody noses happened so often it was “normal” for me to stop playing and simply bleed. The nosebleeds are few and far between now, but I’ll never forget how they felt. Then when I started my period, I started hearing the phrase “symptomatic carrier.”

Initially, I became more aware of what my body was going through because I was a daughter of a man with severe hemophilia A. When I was just 13, I lay awake at night, worrying about whether I really wanted to be on factor for my symptoms. Later, when I became pregnant and had a miscarriage, my doctor told me I had to agree to a blood transfusion or I wouldn’t make it. I’ve now had three boys and one has hemophilia, and I suffered significant bleeds for about two months after each delivery.

Then my eye injury happened. I woke up one day and could not see out of my left eye at all. I was told there was a small amount of blood collecting in the middle of my eye. The doctor said it was an easy surgery but then, while I was under anesthesia, he had to perform emergency surgery to reattach my retina because it became detached because of the pressure of the blood filling up in my eye. If I’d been a “real” hemophiliac, that would



have been called a “spontaneous micro-bleed.” But for me there was no label or diagnosis; it was simply “unknown”—because I’m just a carrier, right?

I stayed away from our community for a long time, but after 20 years I reconnected and was educated on the fact that “symptomatic carrier” is an outdated diagnosis. It took women with von Willebrand’s Disease to essentially force me to take my own health as a woman with a bleeding disorder as seriously as I take my son’s hemophilia. It was Female Factor that brought me back. I was given the amazing opportunity to help create a program for women at my local chapter who are affected and connected in the community and Female Factor was born. And, in a way, I was reborn.

It took women with von Willebrand’s Disease to essentially force me to take my own health as a woman with a bleeding disorder as seriously as I take my son’s hemophilia.

Along with many other women in the community, I used HFA’s Blood Sisterhood program to plan events that were fun but educational. Women from all over my home state of California can come together to talk their bleeding disorders and other topics that help to improve their quality of life, including dealing with PTSD, trying yoga, as well as tips on stress management and healthy eating. The information is great, but the most valuable takeaways for me are the friendships, connections, and bonds. When I didn’t have anyone to sit with me at the eye doctor’s and I was scared, they were there holding my hand. When I needed to be rushed to another state to get properly diagnosed before my first surgery which could potentially have taken my eye, they were there in my heart, sharing my fear.

The information is great, but the most valuable takeaways for me are the friendships, connections, and bonds.

I would never have had that kind of support outside this very special sisterhood. These events create a safe space where women in the community can open up, make friends, surround themselves with love and support. I love my bleeding disorders community so much: I'm surrounded by women who know firsthand what I'm going through. They don't call me crazy, and, most importantly, they don't let me give up. When I feel like I'm hitting bottom, they rub my back until I'm ready to get up again. They don't let me make excuses about not taking better care of myself. When I thought I wasn't strong enough to fight for myself, they reminded me that I was.

Now that I have my diagnosis as mild hemophiliac, I have a treatment plan in place should something ever happen to me again. Unfortunately, I have yet to find an HTC that will help me prevent future spontaneous micro-bleeds, will even talk to me about the permanent damage I have in my eye, or will acknowledge the constant lower back and hip pain I experience. Change comes slowly.

Do I want to take medicine they don't use on men with hemophilia and that may cause seizures? No. I want the same kind of care I watched all the men with hemophilia in my family get. I want my own team, one that won't suggest I take my ovaries out just to stop the bleeding. I tell them: the bleeding is natural, not stopping isn't. I need a team that will treat my symptoms and not just my factor level. I wake up tired and in pain and, frankly, tired *of* the pain. But I'm not giving up; my blood sisterhood won't let me. I see men with hemophilia having daughters and I don't want them going untreated and ignored like I was for so long. Yes, we are uncommon but we are out there! We are getting our diagnoses and fighting for a better treatment, so you're not alone. There is a whole sisterhood waiting to help. Thank you, Female Factor, and Blood Sisterhood.

Christa is a mild hemophiliac and a massage therapist. She's also a mother, friend, volunteer, and sister. Having received a late diagnosis in her own life, Christa hopes to bring attention to the many women in our community who may wrongly consider themselves "just a carrier." ■ ■

We are getting our diagnoses and fighting for a better treatment,
SO YOU'RE NOT ALONE.
There is a whole sisterhood waiting to help.



Excerpt From *Blood on Their Hands*

How Greedy Companies, Inept Bureaucracy, and
Bad Science Killed Thousands of Hemophiliacs

Eric Weinberg and Donna Shaw

Blood on Their Hands is an inspiring, firsthand account of the legal battles fought on behalf of hemophiliacs who were unwittingly infected with tainted blood. As part of the team behind the key class action litigation filed by the infected, young New Jersey lawyer Eric Weinberg was faced with a daunting task: to prove the negligence of a powerful, well-connected global industry worth billions. Weinberg and journalist Donna Shaw tell the dramatic story of how idealistic attorneys and their heroic, mortally-ill clients fought to achieve justice and prevent further infections. A stunning exposé of one of the American medical system's most shameful debacles, *Blood on Their Hands* is a rousing reminder that, through perseverance, the victims of corporate greed can sometimes achieve great victory.

Chapter 15 | Of Sheep and Men

The majestic, wood-paneled courtroom in Chicago was filled with lawyers and nearly one hundred hemophiliacs and their families from across the nation. It was January 30, 1995, and three judges from the Seventh Circuit Court of Appeals had a momentous decision to make. Would the industry's petition to decertify the class action prevail? Or would these hemophiliacs, and thousands more like them, be permitted to sue as a group, against the industry that had poisoned them for decades?

Sitting in judgment were Chief Judge Richard Posner and Circuit Judges William Bauer and Ilana Rovner. David Shrager was supposed to present the plaintiffs' argument, but there was an illness in his family and he could not attend, so another Philadelphia attorney, Dianne Nast, took his place. Douglas Fuson, counsel for Armour, represented the defendants.

Among those in the audience was little Roger Holt. Strapped into a special wheelchair that propped his head upright, he barely resembled the nine-year-old Mets fan who had walked into Weinberg's law office less than two years earlier. Roger was dying of AIDS and had difficulty speaking after being stricken by a mysterious neurological and motor-coordination condition the previous summer. The former first baseman was now suffering from muscle spasms, seizures, and blindness.¹ But his mind was still sharp and when he heard something he didn't like, he moaned loudly. Who had the nerve to hush or remove him? Nobody.

Fuson argued that it would be unfair and a waste of court time for the companies to defend themselves in a class action only to be forced to make the same arguments in other cases. He noted that Armour alone was a defendant in 263 individual lawsuits.

Judge Posner asked most of the questions and seemed skeptical of the class certification from the start. The companies, he reminded Nast,

have won 13 out of 14 cases. They're doing well. You're doing badly. You have a chance with a class action to turn the tables on them in a truly dramatic way. For one thing, you have the chance of upping the number of plaintiffs from 300 or 400 or 1,000 to 20,000. I should think they would be concerned that if this class certification is upheld, they will be forced to settle, because their potential liability is so great, even though their chances of winning are probably better than your chances.²

He referred to the viral-inactivation theory as "exotic" and suggested that, while some state courts might support it, others might think it went too far, since the laws on foreseeability varied from state to state.

"I don't think that it is exotic at all," Nast replied. "I think it's almost a textbook question on a law school exam of what foreseeability is about."

Judge Posner, a prominent, much-cited expert on the economic impact of legal decisions, also asked her how much money the plaintiffs would seek in damages. Nast said they did not have a specific number but emphasized that "we don't want to bankrupt these companies...That's not going to help the class that we represent."

As he listened, Weinberg feared the judge was ignoring the value of the MDL, the Multidistrict Litigation. It was obtaining new information that had never been produced before. But he was especially disturbed by Judge Posner's concerns related to potential economic impact, since the companies had not raised the issue in their petition. Indeed, they had done the exact opposite: they had filed financial statements with the U.S. Securities and Exchange Commission asserting that the litigation would have no material effect on their businesses. One of the two basic objectives of the nation's "truth in securities" law is to "prohibit deceit, misrepresentations, and other fraud in the sale of securities," according to the SEC website.³ So presumably, the companies were truthful in their filings.

Then Judge Posner proceeded to stun the courtroom by comparing HIV-infected hemophiliacs to a flock of sheep swept off the deck of a ship, based on a British legal case from 1874.

"The law required a certain type of fencing on a ship to separate the animals in order to prevent contagion," he explained to the courtroom. "And the defendant failed to put in this required

fencing, and there was a storm and all the animals were washed overboard because they did not have the fencing."

But the ship owner was not held liable, Judge Posner noted, because the legal purpose of the fence was only to prevent the spread of disease, not to keep the livestock from drowning.

"There was no duty with respect to this different risk," he said. "Now, isn't it conceivable that a state might say well, there is a duty to act with reference to a risk of hepatitis B, but not with respect to an unknown and even more lethal virus?"

Several audience members gasped. To them, it was bad enough to suggest that the companies had no obligation to sell safe medicines because they did not foresee HIV—even though, for many years before that, they had knowingly sold products contaminated with hepatitis. But was Judge Posner really comparing them to barnyard animals, and was he really suggesting that sheep washed overboard could be compared to the poisoning of thousands of innocent human beings?

Yes. He was.

Roger moaned, his indignant cry ringing through the courtroom.

Judge Posner said the court would take the case under advisement.

ON FEBRUARY 23, 1995, lobbying by what was now a well-organized hemophilia community paid off. The Ricky Ray Hemophilia Relief Fund Act was introduced in the U.S. Congress by Representative Porter J. Goss of Florida, a Republican, who called the HIV epidemic among hemophiliacs a "horrifying" tragedy for which the government was partly to blame. The bill, named for a Florida teenager who died of AIDS in 1992, would establish a \$1 billion compensation fund, with each infected person or survivor eligible to receive up to \$125,000.

The proposed legislation was sharply critical of the government, stating that it had "failed to fulfill its responsibility to properly regulate the blood-products industry" by not requiring earlier use of available technology to cleanse clotting drugs. According to the bill, which had twenty-two Democratic and Republican cosponsors, this technology had been available before 1980, and federal regulators had allowed contaminated products to remain on the market as late as 1987.

In New Jersey a few weeks later, the statute "window" bill also got a boost when the state senate's Judiciary Committee unanimously backed it. Phyllis Hayes, a Weinberg client and Hackensack resident who had lost her son in 1993, spoke for the dozens of victims and family members who had listened

silently, holding aloft photos of loved ones killed by AIDS, as the lawmakers had discussed the measure. “We’re not here just for us,” she said. “We’re here for a whole community. We need your help.”⁴

Not long after came the unanimous approval of the state assembly’s Health and Human Services Committee. Assemblywoman Loretta Weinberg, a Democrat from Bergen County, said statistics showed that most hemophiliacs born before 1985 had contracted HIV.

“This is a case that... involves morality and an expectation of decent health care,” she railed. “This is the United States of America.”⁵

Such progress in Washington and Trenton fueled a heady optimism. At that point, the annual medical costs for hemophiliacs infected with HIV and hepatitis C were well into six figures. At least seventeen other nations already had established government compensation programs; ultimately, there would be more than twenty, with mean awards ranging from \$37,000 to \$400,000.⁶

But on March 16, the Seventh Circuit brought the community back to earth: By a 2-1 vote, it overturned the class action, citing the risk of “a monumental industry-busting error.” Judges Posner and Bauer, with Judge Rovner dissenting, ordered Judge Grady to decertify the class action. To Weinberg, the decision seemed ungrounded in any medical or scientific reality. So many of their expert witnesses now strongly endorsed the plaintiffs’ arguments. Thousands of documents being handed over by the defendants appeared to back that position. The discovery process was working. It was achieving precisely the goals that were intended by the justice system.

The appeals court, however, seemed to acknowledge none of this, assuming instead that the history of the litigation, and all of the losses in individual cases, defined the new case. And it ridiculed the viral-inactivation theory.

Writing for the majority, Judge Posner said that Judge Grady had exceeded “the permissible bounds of discretion,” in part because he was “forcing these defendants to stake their companies on the outcome of a single jury trial, or be forced by fear of the risk of bankruptcy to settle even if they have no legal liability.” He added that “preliminary indications are that the defendants are not liable for the grievous harm that has befallen the members of the class.”

“A notable feature of this case . . . is the demonstrated great likelihood that the plaintiffs’ claims, despite their human appeal, lack legal merit,” he said.⁷

So, as he had in court, Judge Posner worried about the economic impact on the companies, even though they had not mentioned it in their briefs. He appeared to have ignored the economic impact on the victims, some of whom were being bankrupted and evicted from their homes.

Judge Rovner cast the dissenting vote, calling the majority decision an “extraordinary step” and noting that “the Supreme Court has consistently cautioned that mandamus is a drastic remedy to be employed only in the most extraordinary of cases.”

Regarding the economic issue, she pointed out that “defendants did not offer that rationale in support of their petition. . . . The burden of proving irreparable harm lies with the party seeking mandamus relief, not with the court, and defendants wholly failed to meet that burden here.”

This was a devastating loss to the hemophilia community. For most, a class action seemed to be their only hope. In New Jersey it was doubly wounding, given the earlier decision by Judge Hamlin to deny the class there.

Judge Posner recognized this reality in that he offered hope not to the hemophiliacs but to the companies, saying that any additional cases most likely would be dismissed.

“More might be filed,” he wrote, “but probably only a few more, because statutes of limitations in the various states are rapidly expiring for potential plaintiffs. The blood supply has been safe since 1985. That is ten years ago.”

Weinberg had a vision of that quote being copied into motions to dismiss all over the country.

The Steering Committee filed a motion seeking a rehearing by the full appeals court. It was denied by a 5-3 vote. There was, however, a sliver of hope. The plaintiffs still had their Chicago trial date of October 2, 1995—now, not for the thousands of people they had hoped to represent, but at least for Jonathan Wadleigh, the lead plaintiff in the class action. And there was still the MDL.

Could the plaintiffs ask the U.S. Supreme Court to review the appeals court decision? That, too, was a possibility, but the vast majority of such petitions failed. The community and its lawyers had some deciding to do, but the Steering Committee members were unanimous in agreeing they had to preserve the trial date. Once again, the lawyers would regroup and get ready.

Meanwhile, in neighboring Canada, a new front had opened that would produce even more explosive revelations about the global plasmaproducts industry, and its relationship with government regulators and blood bankers. ■ ■

“Will make your blood boil

at the inhumanity of people who knew they were killing patients by the thousands and kept right on, caring for themselves and their pocketbooks. Eric Weinberg and Donna Shaw tell a powerful human story that is hard to put down and will be even harder to forget.”

—David Cay Johnston,
Pulitzer Prize-winning investigative reporter and best-selling author

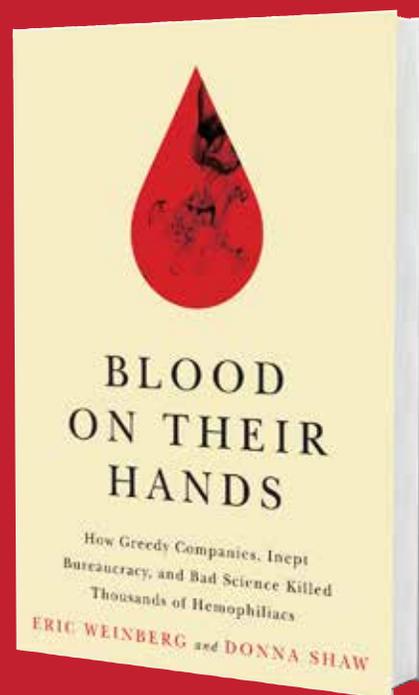
“Unveiling the suffering that devastated families know could have been entirely prevented

Weinberg, a member of the legal team behind a 1994 class action negligence lawsuit, lends astounding detail to the suffering of unwitting patients... The authors make a powerful and important case.”

—Publishers Weekly

“An impressively informative, thoughtful and thought-provoking expose of one of the American medical system’s most shameful debacles in living memory...”

—Willis M. Buhle, *Midwest Book Review*



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HFA Awards \$10,000 in Educational Scholarships

Each year, HFA awards scholarships to promising students in the bleeding disorders community. A total of four scholarships ranging from \$2,000 to \$4,000 are awarded in these three categories:

Educational Scholarship

Two educational scholarships were awarded in the amount of \$2,000 each to students with a bleeding disorder who were seeking a post-secondary education from a college, university or trade school. Applicants were asked to submit an essay answering the questions: How has being a member of the bleeding disorders community influenced how you see the world?

Parent/Sibling/Child Educational Scholarship

One scholarship was awarded in the amount of \$2,000 to the immediate family member of a person with a bleeding disorder who was seeking a post-secondary education from a college, university or trade school. Applicants were asked to submit an essay answering the question: How has being a member of the bleeding disorders community influenced how you see the world?

Medical/Healthcare Services Educational Scholarship

One scholarship was awarded in the amount of \$4,000 to a student pursuing a degree in the medical/healthcare services field. Applicants were asked to submit an essay answering the question: What are the most important issues facing the bleeding disorder community today?

2017 Educational Scholarship Recipients:

ANTHONY PITCH

HFA Educational Scholarship

University of Nevada, Las Vegas | Las Vegas, Nevada



“All of my goals are bound to higher education, ultimately I want to become a professor and impact people’s lives in the most positive way. My life has been somewhat different than most people. Having a bleeding disorder has prevented me from doing some of the same things others can do and requires me to work harder to meet my goals. Part of

reaching my goals has consisted of using my personal skills, abilities, and talents, but most importantly, the support of my community and the Hemophilia Federation of America has provided the inspiration, encouragement, and strength to keep moving forward to achieve my dreams.”

“The support of my community and the Hemophilia Federation of America has provided the inspiration, encouragement, and strength to keep moving forward to achieve my dreams.”

PAUL DEBASSIO

HFA Parent/Sibling/Child Educational Scholarship
Rensselaer Polytechnic Institute | Troy, New York



“Ever since I was eight years old, when my brother, Peter, was diagnosed with hemophilia, I found that I had a true passion for medicine. I realized that I could achieve so much, as long as I put my mind to something. Becoming a doctor has always been a dream of mine, and through this scholarship, I am able to pursue that dream and make it a reality.

I will utilize this scholarship towards my studies at Rensselaer Polytechnic Institute and will graduate with a major in Biology on a PreMed track so that I can one day become a doctor and put a smile on the faces of my future patients.”

DAVID CHEUNG

HFA Educational Scholarship
Saint Louis University, School of Medicine | St. Louis, Missouri



“Since my diagnosis of hemophilia, I always knew that I wanted to be a part of something greater. The bleeding disorder community has been that outlet. It has helped me grow as a leader, a community member, and as a person. The community has not only fostered my passion for medicine but also has become my second family. This amazing

scholarship is one step closer to providing comfort and care to the community that has made me who I am today. Continuing on to my first year in medical school, I am both humbled and honored to receive such generous support from HFA.”

ANDREA SCHLOSSER

HFA Medical/Health Services
Educational Scholarship

Case Western Reserve University School of Medicine | Cleveland, Ohio



“I wake up every day and I am so excited that I get to study medicine. My brother was diagnosed with moderate hemophilia B when we were both young. Watching the hemophilia community rally around our family inspired me to go into medicine. I am tremendously thankful for this scholarship, which is supporting my tuition costs in

medical school. I look forward to serving as an advocate for the bleeding disorder community and hope that I am able to impact my patients to the same degree that I was impacted by this community.” ■■

“I look forward to serving as an advocate for the bleeding disorder community and hope that I am able to impact my patients to the same degree that I was impacted by this community.”

Sangre Latina

By Martha Boria, Staff

¡Consejos Saludables a la Hora de Comer en este Nuevo Año 2018!

¡Año nuevo, vida nueva! Y con esto nuevas resoluciones para este nuevo año que comienza. Después de las fiestas navideñas, para muchos estar sano y comer bien es lo más importante. Este puede ser el momento de fijar y hacer nuevas cosas o puede ser momento de consolidar lo que habías querido hacer hace tiempo. Para que tus metas puedan ser exitosamente cumplidas, es importante que te sientas renovado y enfocado. A continuación, te presentamos algunas ideas que pueden ayudarte.

Receta nutritiva para hacer con sus hijos.

Ingredientes:

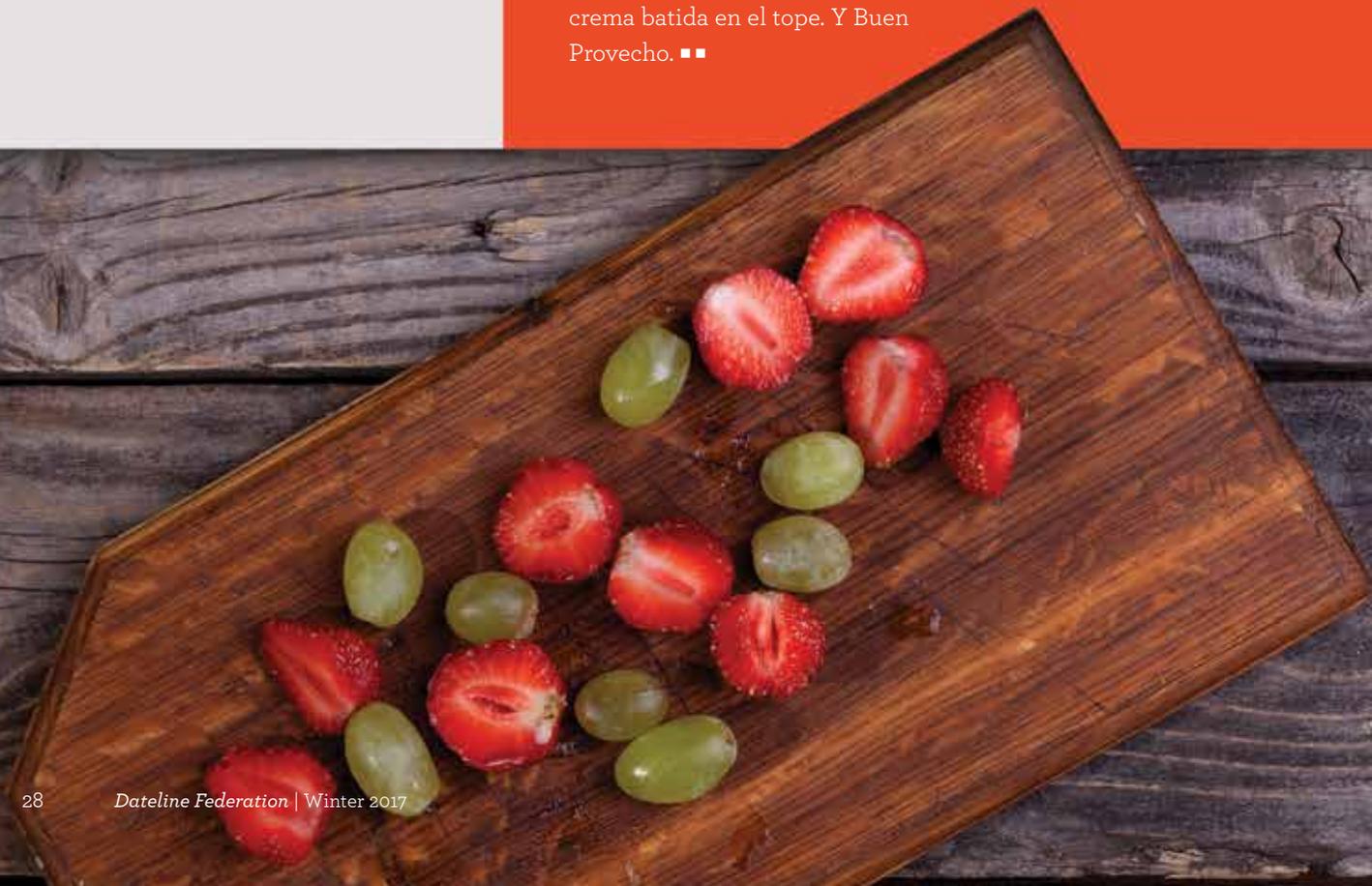
10 fresas	Crema batida baja en calorías
10 uvas verdes	4 rodajas de piña
1 naranja	2 kiwis
Polvo de canela	Sirope de caramelo bajo en calorías

Preparación de la ensalada de frutas con crema batida

1. Lave y pele las frutas, cortarlas en trozos pequeños. Los niños pueden ayudar en el lavado de las frutas. Tenga cuidado si los va a dejar cortar las frutas.

2. Elija un envase para poner las frutas ya lavadas y cortadas. Añadir el sirope de caramelo y polvo de canela. Mezclar todo muy bien y llevar el envase a la nevera para enfriar un poco.

3. A la hora de servir, acompañe la ensalada de frutas con un poco de crema batida en el tope. Y Buen Provecho. ■■



Doce Consejos Saludables Para Comer Sano en el 2018.



Disfrute de la cocina, planifique un momento para la actividad, incorpore recetas saludables en sus comidas y no se limite a disfrutar de sus comidas favoritas, pero con cautela. A la larga, su mente y su cuerpo se lo agradecerán.

- 1 Sea realista.** No trate de perder de peso de una sola vez.
- 2 Planifique el tiempo para el ejercicio.** El ejercicio ayuda a aliviar el estrés de después de las fiestas y a prevenir el aumento de peso. Pruebe caminar a paso corto dos veces al día. Zumba en la casa es una buena alternativa (no importa si tiene dos pies izquierdos y no tiene ritmo). Hágalo divertido e incorpore a toda la familia.
- 3 No se salte las comidas.** Tome pequeñas meriendas cada 2 horas para controlar su apetito durante el día.
- 4 A la hora de servirse la comida.** Elija sus comidas favoritas y omita su menos favorito. Incluya vegetales y frutas para mantener su plato equilibrado.
- 5 Salte los platos de acompañamiento pesados.** Ignore la cremosa cacerola y en su lugar, elija llenar su plato con vegetales asados y ensaladas verdes.
- 6 Coma hasta que esté satisfecho, no relleno.** Saboree sus delicias favoritas mientras come porciones pequeñas. Siéntase, póngase cómodo y disfrute.
- 7 Coma lentamente.** De esta manera, podrá saber cuándo se siente lleno y evitar comer en exceso.
- 8 Tenga cuidado con las bebidas.** El alcohol puede disminuir las inhibiciones e inducir a comer en exceso; Las bebidas no alcohólicas pueden estar llenas de calorías y azúcar. ¡Elija agua!
- 9 Si come de más en una comida, haga lo siguiente.** Se necesitan 500 calorías por día (o 3,500 calorías por semana) por encima de su consumo normal / de mantenimiento para ganar una libra. ¡Es imposible ganar peso con un pedazo de pastel!
- 10 Tome el enfoque de la comida.** Si le gusta confeccionar galletas, pasteles y postres use esa energía y creatividad para hacer proyectos en familia. Planifique actividades grupales con familiares y amigos que no sean solo comida.
- 11 A los hispanos nos encanta alargar las fiestas navideñas y si en esta época lo invitan a alguna reunión o fiesta.** Traiga su propio plato saludable. Esta puede ser una forma educada de contribuir a la comida de la fiesta o reunión.
- 12 Practique la cocina saludable.** Preparare los platos favoritos con menos grasa y menos calorías ayudará a promover una alimentación saludable. Incorpore algunos de estos consejos de cocina simple en las recetas tradicionales para que sean más saludables. ■ ■

Responding to Pain

By Michael Bishop, Staff

It's always been difficult for me to analyze inhibitors as they relate to my hemophilia, as they've always been there. I don't remember a time where they weren't a part of my life. But now that I'm older, have had a chance to meet other hemophiliacs, understand different diagnoses (and the associated qualities of life), I think it's become easier for me to reflect on what my inhibitor has meant for my life as a person with hemophilia. I'm happily at a point where I can analyze it without being overly pessimistic. There are better treatments available, and new treatments on the horizon, but even without those, I think I'm a much more contented person, even with this objectively burdensome presence added to my life.

The central difference between me and someone without an inhibitor is the medication. I'm a severe hemophilia B patient, and I have an anaphylactic allergy to factor IX products, so tolerization has never been an option for me. The half-life of my clotting factor is roughly two hours. That means, for my entire life, prophylactic treatment hasn't been an option for me either. This is fine—it just means that I was forced to become accustomed to pain quite early, as were my parents. There was the physical pain for me and the emotional pain for them. And of course I have to cope with the nagging pain of the persistent, but unlikely, dream that someday I just *might* be able to become a professional skateboarder! Pain is probably the



A mistake I made early in my life was consistently trying to wish the pain away.

character most central to the story of a child with inhibitors. It's typically the villain in the story that no one really wants to talk about, for fear of sounding too discouraging, but it's one character that every inhibitor patient and their family knows all too well.

A mistake I made early in my life was consistently trying to wish the pain away. My mother and father would do the same, because the last thing they wanted to see was their child in pain. All the guidance we ever received about pain essentially boiled down to the old maxim "This too shall pass." It's a reasonable sentiment, but by the time I was nine, I began taking it with a grain of salt. Knowing that this ankle bleed will pass, but there's a knee bleed in my near future. Knowing that knee bleed will pass, but my nearly-fused, arthritic knee will never heal itself. Knowing that even if it did, I would never get back those days I wasted wishing the pain away so I could run around with my friends.

I'm writing this at an absurdly late time of night because I have a bleed and can't sleep. I'll probably take a personal day from work tomorrow because I know I won't be able to get any sleep tonight. It reminds me of the nights as a kid when I would lay awake in my bed, waiting for my mom to wake up for work so I could tell her I wasn't going to be able to go to school. It reminds me of the days when I had to act to my friends like I was excited to have the "day off" school, when all I wanted in the world was to be there with them. This is the time when you just want whatever hardship you're going through to be over, so you can go back to what you would like your normal life to be.

I think the most difficult part of being an active member in the community and working in the industry is having new parents, particularly parents of inhibitor patients, ask me what their future looks like, what their child's future looks like. The truth

is, I'm really not sure. With new options available in treatment, and the ones that are coming, added to all the other variables that could make their family's life much different than mine, it's always a difficult question to answer. The only honest answer I can give them is: I don't know, though I suppose that isn't the whole truth. I certainly know a lot of pain is coming their way. Maybe it'll be less pain than I had. I certainly hope it will be less, but there will be pain nonetheless. The fact that others, including me, went through more pain, certainly won't make their pain any easier. And to be honest, there isn't a piece of advice, or any combination of wise words, to make it go away. But, speaking as one who has probably intellectualized their hurting more than the average person, I can say that pain isn't a flatly negative experience.

One thing I know for sure is that whatever pain these families will feel, it will elicit a response within them. It will force them to do something about it. Maybe the response will be that the children will grow up and work for an organization that helps children like them, and their families. Maybe it will lead them to write an essay at that absurdly late time of night with a conviction and sense of purpose that they seldom feel in discussing any other topic. Or maybe it will just give them the capacity to tell someone in pain, "I know how you feel," and share that person's aching for a while. Whatever it is, I know that it will bring out of them a sense of purpose that I don't think I could've found anywhere else, and because of that, it holds in it a unique value that should not be discounted or "wished away." I don't believe that anything I tell you will make the pain easier, but I want you to know that making things easier won't necessarily make things better. So, be hopeful in the new treatment. Live like pain is never coming your way again. But when it does, please don't be disappointed. Give it a response like it never expected. ■■

Live like pain is never coming your way again.

But when it does, please don't be disappointed.

GIVE IT A RESPONSE LIKE IT NEVER EXPECTED.

Now Approved

A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®.

We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use.

HEMLIBRA may cause the following serious side effects when used with 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 signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **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 the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

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.



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.

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

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

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

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- **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 with hemophilia A with 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

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
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 11/2017



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Navigating Patient Assistance Programs

HFA's comprehensive list of available programs.

With the uncertainty of healthcare, many in the bleeding disorders community are concerned about the future of cost and access to factor products. Co-payments and out-of-pocket expenses can be devastating on a family's budget. Assistance programs can provide a source of relief.

The HFA team maintains a comprehensive list of programs that are available to the community and updates it regularly. Visit our site to see which of these programs might apply to you and your family:

- **Factor Co-Pay Programs**
- **Product Assistance Programs**
- **Hepatitis C Virus Co-Pay & Patient Assistance Programs**
- **Additional Resources**

**Visit HFA's resource library on
www.hemophiliafed.org today!**





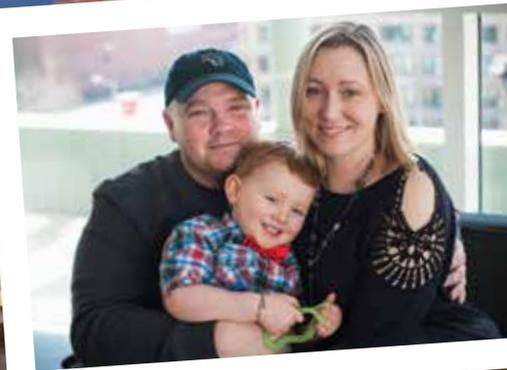
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Symposium offers community members the opportunity to learn and grow. During our powerful sessions, community members can meet and bond on a personal level with other community members and presenters.

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“I enjoy the interaction. Not just between the speakers and the attendees, but among the attendees themselves.”

“The speakers know how to communicate with the Spanish-speaking community.”

“My favorite part of Symposium was the knowledgeable speakers who could easily and effectively answer the questions and concerns expressed during the presentations.”