# CHAPTER *Factors*

WINTER 2017

Midwest
Hemophilia
Association

# 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]

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## 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 January 2, 2017.



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# News and Notes

As we close out the year I would like to thank our Industry Partners who have not only supported us financially, but also provided content and speakers for MHA's educational programming. When I say "partner" I truly mean it. MHA appreciates the knowledge that they bring to the table. Many, if not most, of our Industry colleagues cover multiple states and multiple chapters. Their time is a valuable commodity, and I personally appreciate what they give to MHA. The companies are listed below. The next time you see them, make sure you thank them for being part of our mission.

# QUICK NOTES

## President's Message

I would like to take this opportunity to talk about the role and importance of our dedicated volunteers. While they are not on the board of directors they are the cornerstone in which the rest of the MHA is built. The definition of a volunteer according to Webster's is "a person who voluntarily offers himself/herself for service or undertaking." Our volunteers are the "boots on the ground" and the beating heart of MHA. They advocate for themselves and others to bring awareness, finances and energy to the bleeding disorder community. They are chairpersons of committees, committee members, fundraisers, and event coordinators.

Volunteers have seven key traits which make them unique.

1. **Volunteers are results driven.** They want their cause to generate a positive impact for the chapter. This means they will implement great programs, meaningful and successful fundraising events, and attract other volunteers just like themselves. The underlying drive is that they are motivated by the bottom line results.
2. **Volunteers have passion.** They bring the best to whatever they do, especially to their volunteer effort. When those efforts are combined with their passion, the results are incredible. Their passion will continue to expand this organization to places you couldn't imagine.
3. **Volunteers have a collaborative mindset**. Our volunteers understand that MHA runs on a lean budget and must invite others into the organization. In fact, they understand that we need an entire eco-system of excellence to emerge into something even greater. In this capacity, our volunteers work with MHA leaders to identify, cultivate and realize highly value-added partnerships.

4. **Volunteers don't make excuses.** They stick to their commitment. If they say they will do something, they do their absolute best to make it happen. They are also problem solvers and persist until they find a way forward.
5. **Volunteers are a constant champion**. They don't have an off switch, always finding a way to spread the word even if they are making a social media post. They will find a way to bring visibility to the organization and the cause. They strengthen everyone by enlisting their best and brightest friends, family and colleagues.
6. **Volunteers are energizers.** They feel amped when working with others. When volunteers from different backgrounds get together, they always see the best in each other.
7. **Volunteers care.** They think less about what they can get from the experience and more about what they can contribute. However, they still feel meaningful when helping to a difference.

**BRIDGET CASTRO**
**2017 Volunteer of the Year**

I would also like to call attention to our 2017 Volunteer of the Year – Bridget Castro. Bridget is a remarkable volunteer who took over a geographic area in Western Kansas, and built it into a viable entity for MHA, and the many families who live there. Our annual education events in Western Kansas have grown every year. Her commitment and dedication to helping others with in the bleeding disorder community is to be commended. She is so deserving of this

accolade, and we are proud that she is part of the MHA family.

If you are interested in volunteering for MHA, contact our executive director, Mark Cox. He will be glad to talk with you about MHA's volunteer opportunities.

*— Aimee Tempera*

## Youth Advisory Board to be Formed

The Board of Directors and the Executive Director have determined that the goals of the MHA should include increasing youth involvement in MHA and its activities, as well as increasing awareness among young people of MHA's duties and responsibilities.

With that in mind, the board has created a Midwest Hemophilia Association Youth Advisory Board. They will participate and represent the interest and importance on youth related matters coming before members of the Board of Directors, and on other matters relating to the duties and responsibilities of the MHA of interest and importance to young people. The Youth Advisory Board shall consist of not more than three members between the ages of 19 and 23. They shall serve one-year terms and can be reappointed for additional terms, not to exceed a total of three consecutive terms. Members of the Youth Advisory Board shall be non-voting members of the MHA Board of Directors and may participate in the discussions and deliberations of the Board of Directors on all matters as well as advising the Board of Directors on matters important to young people.

Applications for nominations will be made available at the start of 2018.

## Meet HTC Team Member – Stacy Long

I have been a nurse at Children's Mercy hospital for almost 9 years working specifically in Hematology/Oncology. I received my certification in Pediatric oncology/hematology in 2012. I am a local board officer for the Greater Kansas City APHON Chapter. I have been married to my best friend, Jacob Long for 7 years. We have three fun loving kiddos ages 5, 3 and 20 months. So our free time is spent at the zoo, park or in the laundry room. I am excited to be in this position to help families and the communities in which they live in have a better understanding of bleeding disorders. I want to be here to support you and maneuver the health care system and life together.

***Stacy Long, RN BSN, CPHON***

## Get Your Flu Shot!

Flu season is here. It is recommended by the Hemophilia Treatment Center to receive your flu shot yearly! The flu vaccine is the best protection against the flu this season. It takes two weeks for the vaccine to be active in your body so sooner rather than later is recommended. If you are scheduled for your Comprehensive Appointment at Children's Mercy we can provide the vaccine at that appointment. Many primary care offices offer a Flu Clinic which eliminates the need for a co-pay and it's usually a quick in and out. Many pharmacies at CVS, Walgreens, Target, Hy-Vee offer the vaccine as well. For locations near you check *vaccinefinder.org*. You can simply type in your zip code and it will give you locations closest to you where the flu vaccine is offered.

*— Stacy Long, RN, BSN, CPHON*

## 2018 MHA CALENDAR

**March 1, 2018**
**Bleeding Disorder Advocacy Day**
*Jefferson City, MO*

**March 7 – 9, 2018**
**NHF Washington Days**
*Washington, DC*

**March 23 – 25, 2018**
**Women's Retreat**
*Lodge of the Four Season*
*Lake Ozark, MO*

**April 28, 2018**
**Ozarks Pull for a Cure – A Sporting Clay Event**
*Walnut Shade, MO*

**June 9, 2018**
**KC Pull for a Cure – A Sporting Clay Event**
*Powder Creek Shooting Park*
*Lenexa, KS*

**June 16, 2018**
**Western KS Education Event**
*Dodge City, KS*

**June 22, 2018**
**Springfield Education Event**
*Springfield, MO*

**July 14, 2018**
**Wichita Education Event**
*Wichita, KS*

**July 30 – August 3, 2018**
**28th Annual Summer Camp**
*Lake Doniphan Conference and Retreat Center*
*Excelsior Springs, MO*

**August 25, 2018**
**Hemophilia Walk**
*Lenexa, KS*

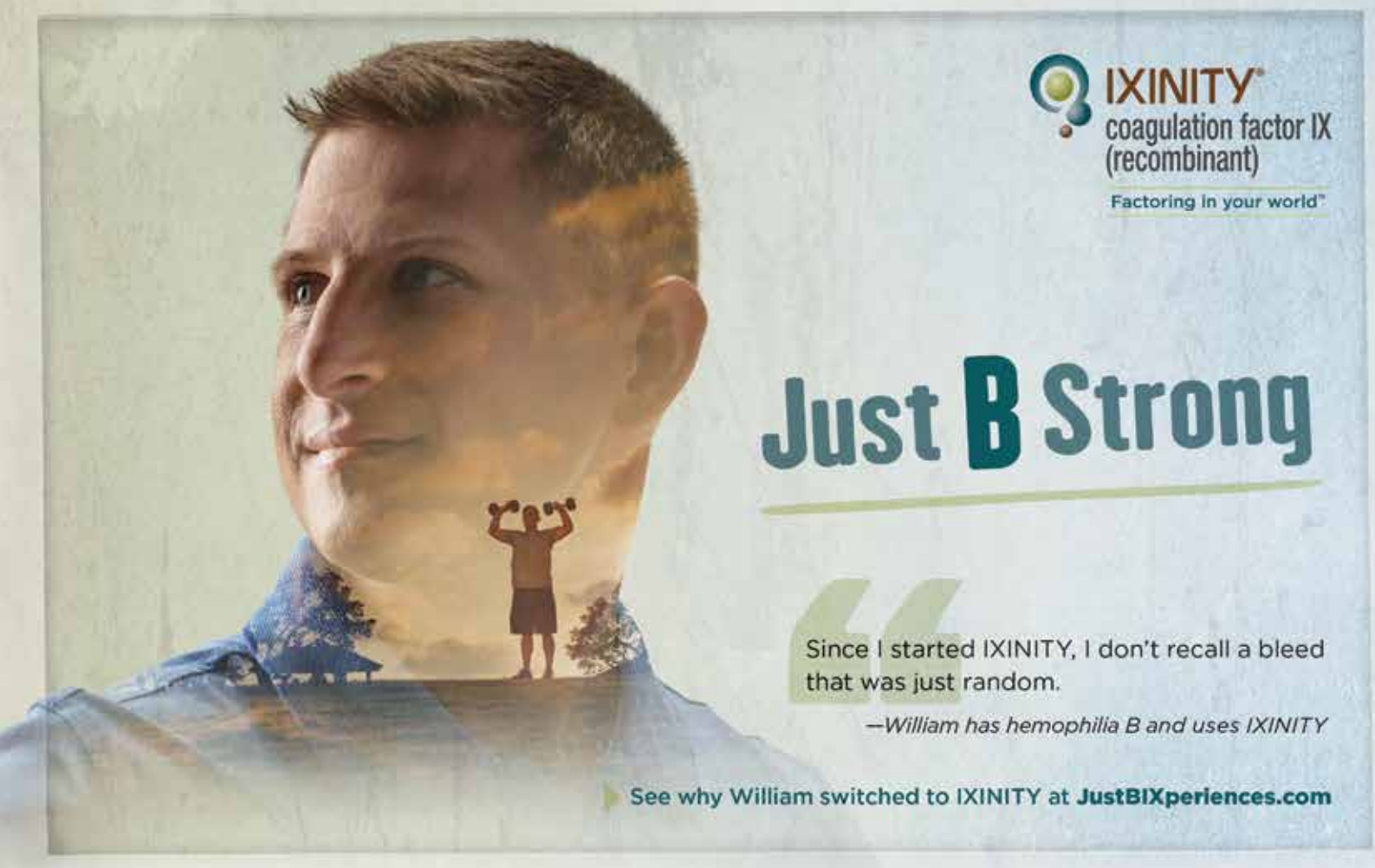
**September 14, 2018**
**20th Annual MHA Golf Tournament**
*Drumm Farm Golf Club*
*Independence, MO*

**September 15-16, 2018**
**26th Annual MHA Family Fun Fair**
*Location TBD*

**October 11 - 14, 2018**
**NHF Annual Meeting**
*Orlando, FL*

**October 27, 2018**
**Wichita Fundraising Event**
*Wichita, KS*

**December 1, 2018**
**24th Annual MHA Banquet**
*Kansas City, MO*
*Location TBD*




This information is based on William's 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.**

Aptevo™ Therapeutics

Aptevo BioTherapeutics LLC, Berwyn, PA 19312

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coagulation factor IX
(recombinant)

Factoring in your world™

**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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# HELPFUL NUMBERS

**KANSAS CITY REGIONAL HEMOPHILIA CENTER**
**1-816-302-6869 • 1-800-236-1713**
Dr. Shannon Carpenter • Dr. William Jennings
Dr. Brian Wicklund • Dr. Jill Moormeier
Rebecca Coney, DNP, APRN, FNP-C
Katie Foote, LMSW • Stacy Long, RN, BSN, CPHON
Lucy Carter Reardon, RN, MSN, APRN, FNP-C

**UNIVERSITY OF MISSOURI HOSPITAL AND CLINICS HEMOPHILIA TREATMENT CENTER**
**1-573-882-9355**
Dr. Barbara Gruner • Dr. Carl Freter
Dr. Tamara Hopkin • Lauren Grana, MSW

**NATIONAL HEMOPHILIA FOUNDATION (NHF)**
**1-800-42-HANDI • www.hemophilia.org**

# NHF's 69th Annual Meeting

## An Attendee's Story

***By Dennis Hisek,***
***MHA Board Member***

When asked if I would be willing to host a camp at Wilderness for hemophiliacs some 28 years ago, my journey of understanding bleeding disorders began. I asked many questions, did some research and decided that the fit was right for the camp and for me. And so my journey goes on.

As I worked and talked with a variety of directors for the camp over the years, I began to understand more about the effects of bleeding disorders and how it could be controlled. I remember vividly those first years of camp: how HIV affected the patients/campers, and some that attended one year were not alive to attend the next. I interacted with the counselors and rejoiced in the time we had together to provide worthwhile and meaningful activities for the campers. The concern and love the counselors had for those affected was evident through my observations of their interactions. I talked with the parents about their struggles to accept and live with the bleeding disorders of their loved ones. I was able to get to know the campers and talk with them about their struggles. I admire the way they arose to the challenges of managing their bleeding disorder and how they strived to be their best in a less than perfect condition.

As I stayed connected in various ways over the years, I became more informed about hemophilia, those affected, the health providers and the pharmaceutical companies that work at making this condition bearable. In the fall of 2017, I was able to attend The National Hemophilia Foundation Annual Meeting in Chicago where I became more informed about different issues concerning bleeding disorders.

The advances being made in therapies from coagulation factor to gene therapy all provide great possibilities. I heard Chris talk about his "summit of achievement" and his quest to climb the summit of Mt. Everest. Yes, there was Chris's story and others of adventure and courage that let us know life can be filled with times of joy even with a bleeding disorder. But there are stories of not so joyful times as well. For example, Elijah was born with a bleeding disorder that was not diagnosed and died just 17 days into her life. Also, the fact that 9 out of 10 bleeding disorders are not diagnosed makes one realize that there is still a great deal that needs to be done.

So, on my journey to learn more about hemophilia and bleeding disorders, I was blessed to meet many people and make friends that will last a lifetime. I also learned we can all do our part to make those with bleeding disorders feel they are people of value and that they can live their lives to the fullest.

# A Note from a Georgia Northway Scholarship Recipient

*By Austin Henry*

Hi, my name is Austin Henry. I have severe hemophilia, factor VIII deficiency, and I have been searching for my place in society. This truth has been a driving force of my passion: to develop a clinic where anyone with a traumatic experience can come and find peace. I want to develop a research clinic that will truly try to help people find relief by realizing their true potential. This dream of mine encompasses anyone. From a soldier who has been critically wounded in combat protecting our freedoms, to a hemophiliac who was never allowed to follow their hearts desire to serve their country because they had a genetic disorder.

My clinic will be based around physical therapy with the intention of finding and discovering new ways to really provide a life of freedom. We all, as hemophiliacs, wish we could achieve things we know are not physically possible. Through new research, and with the help of people who truly care, I know we can find a better way.

That's why I am so thankful to have received the Georgia B. Northway Scholarship from the Midwest Hemophilia Association. Without their help and dedication, I would not be able to see my dreams come true. I am in college to become a physical therapist.

With this degree, I believe I can open up a clinic with a full gym attached and we can all come together to start to find peace. There's so much to learn out there and I believe we are very close to discovering something big in our lifetimes. Something that will bring humanity to a whole new level.


## 2018 MISSOURI BLEEDING DISORDERS ADVOCACY DAY

**THURSDAY, MARCH 1, 2018**
**8:30am to 1:00pm**
**Missouri State Capitol • Jefferson City, MO**

This is your opportunity to advocate directly with your elected officials and for the bleeding disorder's community of Missouri. Sharing your story with legislators is an important and an easy way to be part of the solution to the challenges facing the bleeding disorders community.

**The deadline to register is Friday, February 2nd.**
There will be an Advocacy Training dinner for attendees and a Teen Advocacy Training the night before, February 28th, at the Capitol Plaza Hotel in Jefferson City. Registrants will receive more information as we get closer to the event. Register at ***www.gatewayhemophilia.org/events/mo-lobby-day/***

***Travel Scholarships available to Missouri consumers traveling over 100 miles one way.***

For general information contact:

**BRIDGET TYREY**
**(314) 482-5973 | bridgettyrey@gatewayhemophilia.org**

**MARK COX**
**(816) 479-5900 | mcox@midwesthemophilia.org**

# Being Whole: Women with Bleeding Disorders

Have you ever experienced one of those light-bulb moments? You know, when you look at something for a long time, and then inexplicably see it from a different perspective?

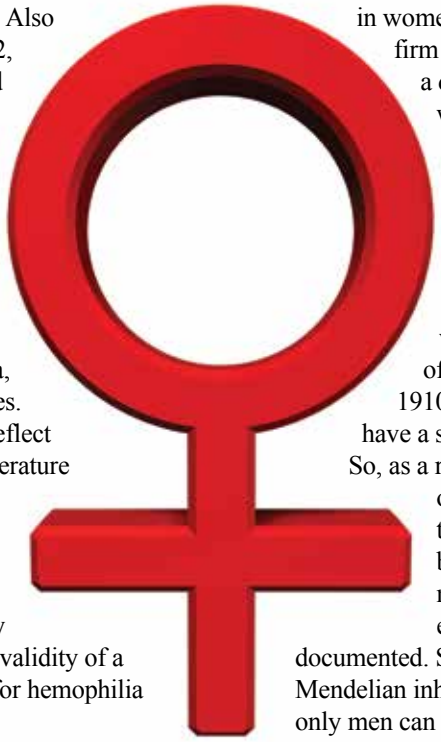
While researching references to women with bleeding disorders, I looked at the Bible, Matthew 9:20-21: *And, behold, a woman, which was diseased with an issue of blood twelve years, came behind him, and touched the hem of his garment; For she said within herself, If I may but touch his garment, I shall be whole.*

That was my light-bulb moment. Could this biblical passage be the earliest written record of a woman with a bleeding disorder? Maybe she had von Willebrand disease, or maybe even hemophilia?

The debate over whether women can have hemophilia is ongoing. In the first known article on bleeding disorders, printed in 1803 in the Medical Repository, America's first medical journal, Philadelphia physician John Conrad Otto stated that only males are affected with a "hemorrhagic disposition," while females are exempt but are still capable of transmitting the disposition to their male children. This is an early observation of what we now know to be the "sex-linked recessive" inheritance pattern of hemophilia—in which we believed only males, having only one copy of the X chromosome, show symptoms of the disorder.

Otto's article on "bleeders" prompted the publishing of additional cases of bleeding disorders worldwide. The opinion that only men suffered from a hemorrhagic tendency was substantiated by nine other American journal articles, plus additional European articles. Then, in 1841, Thomas Smethurst, an English surgeon, reported that women could also have bleeding disorders, and described two female cases subject to hemorrhagic tendency. After this article was published, more cases of women with bleeding disorders were reported.

A characteristic of some medical journal articles, textbooks, and monographs on bleeding disorders in the 1800s is that newly reported cases were added to the number of existing cases in running tallies, so that an international prevalence (number of people living with a disease) was continually being updated. In Germany in 1851, Lange reported on 260 cases of "hemophilia," including 31 females. (The term *hemophilia*, or *haemophilia*, was coined in 1823, and at that time referred to any bleeding tendency.) Also in Germany in 1872, Grandidier reported on 631 cases of hemophilia, including 48 females. Then in 1883, Thomas Dunn from Pennsylvania reported on 780 cases of hemophilia, including 63 females. These summaries reflect the total medical literature of known cases of hemophilia in the 1800s. Yet many members of the medical community still questioned the validity of a medical diagnosis for hemophilia in women.



The first description of a female with a bleeding disorder, later to be identified as true female hemophilia, was in a medical journal article written in 1886 by Sir Frederick Treves, a London surgeon. Florence Parker, a six-year-old girl from a well-known "bleeder" family originating in Essex, presented with obstinate bleeding after a molar extraction. Her family included 11 male "bleeders." The extended family underwent numerous diagnostic investigations by medical experts as the number of identified cases grew to 22 family members, including 5 females. Although Florence died at age 21, shortly after the birth of her first child, her bleeding disorder was diagnosed as hemophilia A based on blood tests of one of her sisters and a nephew. Peter Kernoff and Charles Rizza of England reported this diagnosis in a 1973 medical journal article.

I believe the medical community took a stronger stance against the possibility of female hemophilia once British physicians William Bulloch and Paul Fildes published their extensive worldwide study of the entire Western medical literature on hemophilia in 1911. Bulloch and Fildes stated that the occurrence of hemophilia in women was unsupported by firm evidence. Their study put a damper on tallying women with bleeding disorders because the authors' professional stature was too great to be disputed. And their position that only men could have hemophilia fit in neatly with the simple concepts of inheritance popular in the 1910s—that only men could have a sex-linked disorder.

So, as a result of Bulloch and Fildes's opinions, the realization that women could have bleeding disorders took much longer to be accepted, even as additional cases were documented. Sadly, this simple concept of Mendelian inheritance, and the idea that only men can have a sex-linked recessive disorder, is still held by many physicians. This has prevented or delayed proper diagnosis and treatment of many women's bleeding disorders.

Decide for yourself: Does the biblical story of a suffering woman—who, according to some accounts, spent her money over 12 years in a desperate search to effectively treat her bleeding condition—truly represent the first written report of a woman with a bleeding disorder? Read Matthew 9:20-21. Or listen to 1950s legend Sam Cooke and the Soul Stirrers singing "Touch the Hem of His Garment." This emotionally stirring gospel song, based on the biblical verse, could easily be a motivational theme for women with bleeding disorders.

For a list of sources used for this article, see PEN at *www.kelleycom.com*.

*— by Richard J. Atwood*

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