



# Hemophilia News and Views

Fall Edition 2017

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## Chapter News

Dear Friends,

I am excited to join you as the Executive Director for the Nevada Chapter of the National Hemophilia Foundation (NHF-NV). In my short time in this role, I've already witnessed the strength, compassion and unwavering dedication of so many members of our bleeding disorders community. I hope to do my best, along with Maureen, our Program Manager, and our committed board of directors, volunteers, and families to support and advocate for you.

It has been a tumultuous year in national healthcare policy and changes within the Nevada bleeding disorders community. I want to assure you the NHF-NV is here, and will continue to be here offering support, education and programs to improve your quality of life and quality of care.

I have a lot to learn about bleeding disorders, the needs of our community and how NHF-NV can best serve you. I invite you to help me learn by sharing your thoughts, concerns and

stories. I hope to meet each and everyone one of you and encourage you to come to our upcoming events, stop by the office, or give me a call or email.

Together, with your help, we will continue to build a strong, open, and supportive, chapter network helping to improve the quality of life and quality of care for our community.

Sincerely,

Betsy VanDeusen  
Chapter Executive  
Director

## Annual Meeting & Holiday Celebration

**Sunday, December 3rd**

**12:30 pm – 6:30 pm**

**City of Henderson Convention Center**

**200 South Water Street**

**Henderson, NV 89015**

*We are in need of raffle items. If you can donate something toward the raffle please let us know. If you would like to solicit businesses you frequent, we can provide you with a request letter.*

**RSVP by November 19th**

## **Betsy VanDeusen- Nevada Chapter Executive Director**



With over ten years as a non-profit professional, Betsy has experience in fund raising, direct service to youth, administration, special events and volunteer management. Betsy has worked with many Las Vegas area nonprofit organizations including Immunize Nevada, The Animal Foundation, United Way of Southern Nevada, The Boys & Girls Clubs of Las Vegas and Teach For America – Las Vegas Valley. A big believer in giving back to the community, Betsy has a long history of community engagement from serving as an Ameri-Corps Volunteer with City Year Boston, class of 2000 and as a founding member of the Red Rock Rotary Club.

In addition to her professional activities, Betsy helped found the Young Non Profit Professionals Network of Southern Nevada, and has served on the Boards of "Directors of Volunteers in Agencies" and Family Promise and was a founding member of the Sin City Roller Girls – Flat Track Roller Derby League. Betsy holds a BA of Sociology from Colorado College and an MA in Public Service – Non Profit Management from Marquette University.

In her spare time, Betsy enjoys spending time outdoors with her family hiking, backpacking, canoeing and camping.

The Nevada Chapter of the National Hemophilia Foundation is dedicated to improving the quality of care and life for people with hemophilia, von Willebrand disease, and other inherited bleeding disorders through education, peer support, and advocacy.

### **Staff**

Executive Director—Betsy VanDeusen  
Chapter Program Manager—Maureen Salazar-Magana

### **Advisory Board of Directors**

President—Brandi Dawkins  
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Board Member—Tanya Butler  
Board Member—Jacey Gonzalez

Hemophilia News and Views is published 4 times a year by the Nevada Chapter of the National Hemophilia Foundation (NHF-NV). We welcome advertisers. Please contact the office at 702.564.4368 for advertising rates.

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

## **Nevada Chapter of the National Hemophilia Foundation 2017 Program and Events Calendar**

**You can register for all events on our website:  
[www.hfnv.org](http://www.hfnv.org) Go to News & Events/Events Calendar**

**November 3-5, 2017:** Gettin' in the Game  
Phoenix, AZ

**December 3, 2017:** Annual Family Conference & Holiday Celebration  
12:30-6:30 pm, Las Vegas, NV

**December 6, 2017:** Holiday Celebration  
Elko, NV

**December 7, 2017:** Holiday Celebration  
Reno, NV

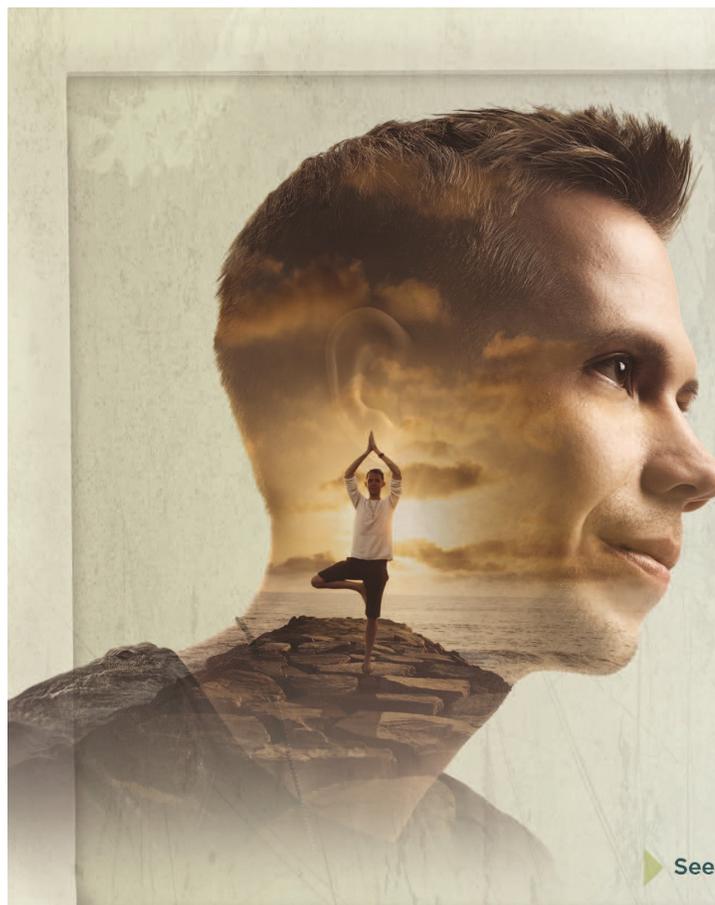
**December 16, 2017:** Posada  
Las Vegas, NV

**Coming Soon**

**February 23, 2018:** Winter Wine Fest 2018  
Las Vegas, NV

**April 16, 2018:** Nevada Hemophilia Golf Tournament  
Red Rock Country Club, Las Vegas, NV

**June 12-16, 2018:** Camp Independent Firefly  
Big Bear, CA





**IXINITY<sup>®</sup>**  
coagulation factor IX  
(recombinant)  
**Factoring in your world<sup>™</sup>**

# Just B Yourself

“Switching to IXINITY was the best decision I ever made with my doctor. Sometimes, I don't feel like someone with hemophilia.”

—James has hemophilia B and uses IXINITY

▶ See why James switched to IXINITY at [JustBIXperiences.com](http://JustBIXperiences.com)

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

## INDICATIONS AND IMPORTANT SAFETY INFORMATION

### What is IXINITY<sup>®</sup>?

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<sup>®</sup>

- 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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

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

Aptevo BioTherapeutics LLC, Berwyn, PA 19312

IXINITY<sup>®</sup> [coagulation factor IX (recombinant)] and any and all Aptevo BioTherapeutics LLC brand, product, service and feature names, logos, and slogans are trademarks or registered trademarks of Aptevo BioTherapeutics LLC in the United States and/or other countries.



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Therapeutics

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## 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](http://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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Part No: 1000973\_1  
CM-FIX-0078

## Parental Dynamics: Holding It Together

### by Cazandra Campos-MacDonald

The National Hemophilia Foundation hosts an annual meeting with workshops, exhibits, and social gatherings for the bleeding disorders community. It's a time when consumers, providers, and industry come together to support one another. When you have been in the community for more than 20 years, the best part is catching up with old friends.

My husband recently attended the 69th annual meeting in Chicago. He had the opportunity to have lunch with a former colleague of mine who has become a dear friend. As they talked over lunch, she told my husband, "I can't believe you and Cazandra are still together after all you have been through." It was funny to hear someone say that because I've never dreamed of being apart from my husband. But when our oldest son, Julian, who is 21, was diagnosed at birth with severe hemophilia, the statistics that scared us the most were the ones about couples divorcing from the stress of a chronic illness.

I remember hearing stories of parents divorcing back in the early days of Julian's diagnosis. Not necessarily because they were having marital problems because of living with a bleeding disorder, but divorcing because they were not able to access insurance that would cover their affected child unless they were apart. I couldn't even imagine what that must have been like for those families. And other families simply could not handle the strain of caring for a child with a bleeding disorder. So often, one parent would shoulder the responsibility of doctors' appointments, ordering factor, learning to infuse, and basically being the primary caretaker while the other parent kept their hands off their child's treatment. I still see that happen all too often in the bleeding disorder community.

I know every family dynamic is different, and comparing one to the other is impossible. But in my home, I can't begin to tell you how grateful I was, and am, to have a partner who shoulders an equal amount of responsibility with my youngest son's hemophilia. My husband was the first of the two of us to access each of our son's ports. It was a very emotional thing for me, and my husband was able to give me some time as he took charge until I

could get myself together and do the same. We balance each other beautifully, never skipping a beat.

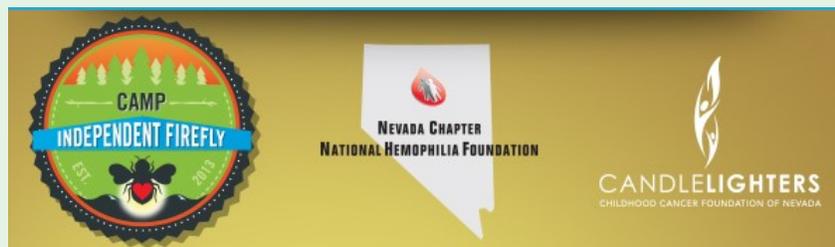
When I think of the many single parents who are doing the best they can to keep their lives as normal as possible for their children, oh, and have a child with hemophilia, I am amazed at how they manage. The same goes for military families who have a spouse who is on duty for months at a time with the other parent left behind to keep the home fires burning and the infusions going.

Today, I give thanks for having a husband who not only balances me out, but also helps to keep our youngest son in one piece by infusing at the drop of a hat. He shoulders an equal, if not larger, load of hemophilia responsibility in our home, and for that, I am grateful.



Cazandra Campos-MacDonald is a motivational speaker, writer and patient advocate for families with bleeding disorders. She blogs about the journey of her two sons with severe hemophilia and inhibitors and has written articles and blog posts for numerous publications. Cazandra's older brother, Ronaldo Julian Campos, died of complications from hemophilia as an infant. She lives with her family, Rev. Joe MacDonald, Julian (21) and Caeleb (11) in Rio Rancho, New Mexico. You may follow her blogs and view her TEDxABQ talk at [www.cazandramacdonald.com](http://www.cazandramacdonald.com).

Note: Hemophilia News Today is strictly a news and information website about the disease. It does not provide medical advice, diagnosis or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or another qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read on this website. The opinions expressed in this column are not those of Hemophilia News Today or its parent company, BioNews Services, and are intended to spark discussion about issues pertaining to hemophilia.



## Save the Date: Camp Independent Firefly 2018

**Camp Independent Firefly 2018 will be taking place  
June 12 – 16, 2018!**

**Online camper applications will be available  
February 1, 2018**

The advertisement has a green-to-yellow gradient background. On the left, four circular photos are arranged around the product name: a person on a bicycle, two young girls, two people playing basketball, and a man's portrait. The text 'NUWIQ®' is in large white letters, with 'Antihemophilic Factor (Recombinant)' below it. To the right, the heading 'Want to Learn More?' is underlined. Below it, contact information for Lynn Barker is provided: 'Contact your Octapharma Representative: LYNN BARKER', 'PHONE: 801-209-9368', and 'EMAIL: Lynn.Barker@Octapharma.com'.

## A Growing Network of Support

### NHF develops two websites just for women.

Symptoms of a bleeding disorder can feel frightening and isolating. The National Hemophilia Foundation (NHF) intends to change that experience by providing two websites for women. With them, NHF will raise awareness for bleeding disorders and give women a place to connect with others.

#### **Obstacles and opportunities**

Women can face several challenges on the road to a diagnosis. Because bleeding disorders often run in families, many women don't even recognize something is off. "We've heard many times, 'Well, I didn't know that a super heavy period that lasted eight days wasn't normal, because my mom had that, too,'" says Corinne Koenig, MA, NHF manager of education and training.

Even if they do suspect a problem, women often find diagnosis can be difficult. That's because the tests for von Willebrand disease, for example, can be skewed by stress, exercise and whether you have an active infection or inflammation. Some tests may have to be repeated. Further, the tests have to be conducted by a specialized lab.

But an accurate and timely diagnosis is crucial. "Women with bleeding disorders are at risk for bleeding with childbirth or surgical procedures," says Chris Guelcher, MS, APRN, PPCNP-BC, a member of the NHF Women with Bleeding Disorders working group and a pediatric nurse practitioner. Both of those require foreknowledge of the specific bleeding disorder and a treatment plan, she adds.

There are also important quality-of-life issues. For example, iron deficiency from blood loss, which can lead to anemia, can inhibit your ability to participate in activities. "If you're constantly exhausted, having headaches and dizziness, you're going to be less productive," says Guelcher.

#### **NEW: Better You Know Website**

NHF's new site, [betteryouknow.org](http://betteryouknow.org), targets individuals who are symptomatic but haven't yet been diagnosed. It uses a screening tool initially developed by Claire S. Philipp, MD, and Ambarina Faiz, MD, at the University of Medicine and Dentistry of New Jersey in Newark. The tool has been validated through a study on women with menorrhagia (heavy menstrual bleeding) conducted in conjunction with six US medical centers and the US Centers for Disease Control and Prevention.

After users answer a series of questions, the screening tool tells them if they may be at risk for a bleeding disorder. The website also offers information on how to find the right healthcare provider and how to best prepare for a healthcare appointment. Further, there is general information on bleeding disorders and how to manage symptoms.

Material on the site can serve as a good starting point for talking with your doctor. "This site will fill in the gap for women who have symptoms but aren't getting the information, diagnosis or care they need," says Kate Nammacher, MPH, NHF director of education.

#### **RENEWED: Victory for Women Website**

The journey to getting a diagnosis can be long and frustrating. Afterward, questions may abound, such as: How will this condition affect my life? What do I do? How do I cope? To help answer those questions, NHF has refurbished and re-launched its Victory for Women website, [victoryforwomen.org](http://victoryforwomen.org).

Previously, Victory for Women existed as an informational site. But anecdotal feedback from women in the community and from a 2015 NHF survey revealed that women wanted a resource that lets them connect with others. "NHF already had a lot of other women's information resources on [hemophilia.org](http://hemophilia.org) and [stepsforliving.hemophilia.org](http://stepsforliving.hemophilia.org), but nowhere on our sites to connect," says Nammacher.

Results from the survey and guidance from women with bleeding disorders helped establish the content on the refreshed website. It will now feature users' stories, poems, artwork and photography. NHF will also launch a podcast series. Each quarter, the site will highlight a woman who has made a contribution to the community. In addition, an "Ask the Expert" section allows women to post questions, which NHF will direct to experts, who will then post the answers.

Women can upload pictures of their art, podcasts, stories and videos, connecting with other women in the bleeding disorders community. "We want this to be a place where women feel they're connected to others who know what they're going through, whether they have a chapter right down the street or 10 hours away," says Koenig.

"It's going to be a space for women to be creative, to tell their stories and to share life's fun moments," says Nammacher.

Both sites offer reliable information and a supportive network to help you on your own path to victory.

Copyright [hemaware.org](http://hemaware.org) July 2016

**Register for Events on NHF Nevada’s Website**

Our website is updated often and gives you the ability to register for programs and events! It is mobile friendly too! Check it out at [www.hfnv.org](http://www.hfnv.org).

It also includes links to national resources!

To register for one of our upcoming programs and events on our event calendar, go to [www.hfnv.org](http://www.hfnv.org) click on News & Events and then go to the Event Calendar.

The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. "Coming together is a beginning. Keeping together is progress. Working together is success."

**Articles in this Newsletter provided by the following websites!**

- [www.hemophilia.org](http://www.hemophilia.org)
- [betteryouknow.org](http://betteryouknow.org)
- [stepsforliving.hemophilia.org](http://stepsforliving.hemophilia.org)
- [hemaware.org](http://hemaware.org)



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# 2017 Hemophilia Walk and 5k!



Thank you for your support!  
Over \$63,000 Raised!



**READY TO GOLF?**  
**Mark your calendars!**  
**Monday, April 16, 2018**

***Red Rock Country Club***

100% of every dollar raised directly support your local chapter's advocacy, education and research initiatives.

501(c) 3 non profit organizations. C4K Tax ID #26-0286469

# **Camp Independent Firefly 2017**

## **Lights, Camera, Action**





## WOMEN ALSO BLEED

Women can have bleeding disorders, too. A bleeding disorder results from a flaw in the body's clotting system. Specialized proteins in the blood are called clotting factors. If they are missing or do not work properly, a bleeding disorder can result. Most bleeding disorders are inherited, caused by a genetic mutation, but some can occur spontaneously. People with bleeding disorders bleed longer, not faster, than those who do not.

You may have a bleeding disorder if you have one or more of the following symptoms:

I have heavy menstrual periods

Bleeding for more than 7 days, from the time it began until it stopped

Flooding or gushing of blood, limiting daily activities such as housework, exercise or social activities

Passing clots that are bigger than a quarter

Changing tampon and/or pad every 2 hours or less on heaviest day I have been told I am "low in iron" or I was treated for anemia

I have bleeding symptoms and someone in my family has a bleeding disorder, such as von Willebrand disease, or a clotting factor deficiency, such as hemophilia

I have experienced heavy bleeding from dental surgery, other surgery, or childbirth and/or have other additional bleeding symptoms such as:

frequent prolonged nose bleeds (longer than 10 minutes) or

prolonged bleeding from cuts (longer than 5 minutes) or

easy bruising (weekly, raised and larger than a quarter)

If you have one or more of these symptoms, please speak with your doctor or other healthcare professional.

The most common bleeding disorder in women and girls is von Willebrand disease (VWD). It affects up to 1% of the U.S. population. VWD is an inherited bleeding disorder. It is caused by a defect in or deficiency of von Willebrand factor, a protein the blood needs for clotting.

Women and girls may also have mild hemophilia ("symptomatic carriers"), meaning that in addition to carrying the gene, they also exhibit symptoms. In some cases, females are diagnosed with hemophilia A, or factor VIII deficiency, or hemophilia B, factor IX deficiency—both of which are hereditary. Further, they can have any of the rare factor disorders, such as factor I, II, VI, VII, XI and XIII deficiency.

Although men and women with bleeding disorders have similar symptoms, such as bleeds into joints and tissues, women can experience added complications during menstruation, pregnancy, labor and delivery. Some doctors are not familiar with bleeding disorders in women, many of whom are undiagnosed or misdiagnosed. Women with undiagnosed and untreated bleeding disorders risk serious complications.

Victory for Women (V4W) is NHF's health initiative to address the critical issues faced by women with bleeding disorders. V4W follows in the footsteps of "Project Red Flag: Real Talk about Women's Bleeding Disorders", which brought significant attention to the many women struggling for an accurate diagnosis and appropriate health care. Now that the flag has been raised, V4W continues the work, seeking to educate all about girls, women and bleeding disorders.

If you have symptoms of a bleeding disorder, it is important to get a proper diagnosis and treatment from a specialist, called a hematologist. In the U.S., there is a network of hemophilia treatment centers (HTCs) that provide comprehensive care to patients with hemophilia and other bleeding disorders. HANDI, the National Hemophilia Foundation's information resource center, can provide information on bleeding disorders and the nearest HTC.



### **NYLI is Now Recruiting!**

Tomorrow's leaders in the bleeding disorders community are being shaped today. That's why the National Hemophilia Foundation (NHF) recruits young adults each year for its **National Youth Leadership Institute** (NYLI).

The three-year program builds individual and professional skills in three areas: advocacy, outreach and non-profit development. As a part of NYLI, you will attend NHF's Annual Meetings, participate in Washington Days on Capitol Hill, and deliver educational workshops for teens and adults at the local level.

If you are 18-24 years old, have a bleeding disorder or a have sibling with one, and are looking for a unique leadership opportunity to effect change and positively influence others, now's your time to apply!

Applications are due by **Monday, October 31, 2017.**

Learn more about the NYLI Eligibility & Selection Process and apply today!

Go to [www.hemophilia.org](http://www.hemophilia.org) and search **NYLI**.

For more information, please contact Marlee Whetten, Education Specialist

212.328.3735 or [mwhetten@hemophilia.org](mailto:mwhetten@hemophilia.org)

**If accepted, all expenses (e.g. travel, hotel, meals) for any NYLI event are covered and/or reimbursed by NHF.**

## **Follow us on Social Media!**

**Like us on Facebook!** [facebook.com/NHFNV](https://facebook.com/NHFNV)

**Follow us on Twitter!** [@NVHemophilia](https://twitter.com/NVHemophilia)

**Follow us on Instagram** [NHF Nevada](https://www.instagram.com/NHF_Nevada)

**Subscribe to our YouTube Channel** [NHFNEvada](https://www.youtube.com/NHFNEvada)



ACTIVE IS crew practice during the week, jogging whenever I get a chance, and biking with friends this weekend

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Antihemophilic Factor (Recombinant)

**BRING IT**

## Designed to prevent and control bleeds—

XYNTHA<sup>®</sup> SOLOFUSE<sup>®</sup> is a factor VIII that can help prepare you to live actively

Visit [XYNTHASOLOFUSE.com](http://XYNTHASOLOFUSE.com) and sign up for your **FREE** demo kit



### What is XYNTHA?

XYNTHA<sup>®</sup> Antihemophilic Factor (Recombinant) is indicated in adults and children for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for the prevention of bleeding during surgery in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and, therefore, is not indicated for von Willebrand's disease.

### Important Safety Information for XYNTHA

- Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction: wheezing, difficulty breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, low blood pressure, or hives. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your healthcare provider if you have had an allergic reaction to hamster protein.
- Call your healthcare provider right away if bleeding is not controlled after using XYNTHA; this may be a sign of an

inhibitor, an antibody that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests to monitor for inhibitors.

- Across all clinical studies, the most common side effects (10% or more) with XYNTHA in adult and pediatric previously treated patients (PTPs) were headache (26% of subjects), joint pain (25%), fever (21%), and cough (11%). Other side effects reported in 5% or more of patients were: diarrhea, vomiting, weakness, and nausea.
- XYNTHA is an injectable medicine administered by intravenous (IV) infusion. You may experience local irritation when infusing XYNTHA after reconstitution in XYNTHA<sup>®</sup> SOLOFUSE<sup>®</sup>.

**Please see brief summary of full Prescribing Information for XYNTHA and XYNTHA SOLOFUSE on the next page.**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

\*This card will be accepted only at participating pharmacies. This card is not health insurance. No membership fees.

### Need help accessing Pfizer medicines?

Pfizer RxPathways program may be able to help. Call **1-888-327-7787** or visit [www.PfizerRxPath.com](http://www.PfizerRxPath.com).

Pfizer RxPathways is a joint program of Pfizer Inc. and the Pfizer Patient Assistance Foundation™.



**Save on XYNTHA<sup>®</sup>**  
Terms and conditions can be found at [XYNTHA.com](http://XYNTHA.com).





**Antihemophilic Factor (Recombinant)**



**Antihemophilic Factor (Recombinant)**

R<sub>x</sub>only

#### Brief Summary

See package insert for full Prescribing Information, including patient labeling. For further product information and current patient labeling, please visit [XYNTHA.com](http://XYNTHA.com) or call Pfizer Inc toll-free at 1-800-879-3477.

Please read this Patient Information carefully before using XYNTHA and each time you get a refill. There may be new information. This leaflet does not take the place of talking with your healthcare provider about your medical problems or your treatment.

#### What is XYNTHA?

XYNTHA is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia A. Hemophilia A is also called classic hemophilia. Your healthcare provider may give you XYNTHA when you have surgery.

XYNTHA is not used to treat von Willebrand's disease.

#### What should I tell my healthcare provider before using XYNTHA?

Tell your healthcare provider about all your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if XYNTHA may harm your unborn baby.
- are breastfeeding. It is not known if XYNTHA passes into your milk and if it can harm your baby.

Tell your healthcare provider and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

#### How should I infuse XYNTHA?

**Step-by-step instructions for infusing with XYNTHA are provided at the end of the complete Patient Information leaflet.** The steps listed below are general guidelines for using XYNTHA. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedures, please call your healthcare provider before using.

**Call your healthcare provider right away if bleeding is not controlled after using XYNTHA.** Your body can also make antibodies against XYNTHA (called "inhibitors") that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests from time to time to monitor for inhibitors.

Call your healthcare provider right away if you take more than the dose you should take.

Talk to your healthcare provider before traveling. Plan to bring enough XYNTHA for your treatment during this time.

#### What are the possible side effects of XYNTHA?

**Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction:**

- wheezing
- difficulty breathing
- chest tightness
- turning blue (look at lips and gums)
- fast heartbeat
- swelling of the face
- faintness
- rash
- hives

Common side effects of XYNTHA are

- headache
- fever
- nausea
- vomiting
- diarrhea
- weakness

Talk to your healthcare provider about any side effect that bothers you or that does not go away. You may report side effects to FDA at 1-800-FDA-1088.

#### How should I store XYNTHA?

Do not freeze.

Protect from light.

#### XYNTHA Vials

Store XYNTHA in the refrigerator at 36° to 46°F (2° to 8°C). Store the diluent syringe at 36° to 77°F (2° to 25°C).

XYNTHA can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA at room temperature, carefully write down the date you put XYNTHA at room temperature, so you will know when to either put it back in the refrigerator, use it immediately, or throw it away. There is a space on the carton for you to write the date.

If stored at room temperature, XYNTHA can be returned one time to the refrigerator until the expiration date. Do not store at room temperature and return it to the refrigerator more than once. Throw away any unused XYNTHA after the expiration date.

Infuse XYNTHA within 3 hours of reconstitution. You can keep the reconstituted solution at room temperature before infusion, but if you have not used it in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

#### XYNTHA SOLOFUSE

Store in the refrigerator at 36° to 46°F (2° to 8°C).

XYNTHA SOLOFUSE can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA SOLOFUSE at room temperature, carefully write down the date you put XYNTHA SOLOFUSE at room temperature, so you will know when to throw it away. There is a space on the carton for you to write the date.

Throw away any unused XYNTHA SOLOFUSE after the expiration date.

Infuse within 3 hours after reconstitution or after removal of the grey rubber tip cap from the prefilled dual-chamber syringe. You can keep the reconstituted solution at room temperature before infusion, but if it is not used in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

#### What else should I know about XYNTHA?

Medicines are sometimes prescribed for purposes other than those listed here. Talk to your healthcare provider if you have any concerns. You can ask your healthcare provider for information about XYNTHA that was written for healthcare professionals.

Do not share XYNTHA with other people, even if they have the same symptoms that you have.

This brief summary is based on the Xyntha® [Antihemophilic Factor (Recombinant)] Prescribing Information LAB-0516-5.0, revised 10/14, and LAB-0600-9.0, revised 10/14.

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