ADVOCAacy TRAINING AND RICHMOND DAYS

Becky Bowers-Lanier, Advocacy Consultant VHF and HACA

Mark your calendars for Sunday, January 17th, for our annual Advocacy Training (with lots of opportunities for education, food, and networking). Then on Monday, the 18th it’s “Richmond Days” (Martin Luther King Day), we’ll visit with legislators and their aides and offer refreshments for all at the General Assembly Building. Don’t miss it! For more information, visit the upcoming events page of the VHF website www.vahemophilia.org/index.php/upcoming-events.

Our advocacy work group has met twice in the past few months, focusing on federal and state issues with an impact on our community. At the federal level, we are following H.R. 1239, the Accessing Medicare Therapies Act of 2013. This important piece of legislation will clear up CMS rule language that some health insurers have interpreted to mean that non-profit organizations, like Patient Services Incorporated (PSI), cannot provide premium assistance for policyholders.

We have also heard a presentation on the Patients Access to Treatments Act, which would limit cost-sharing requirements of specialty tier medications. This bill is also a priority of the National Hemophilia Foundation (NHF) and one that we have been working on in Virginia for the past several years. We are awaiting a new bill number for the initiative.

Speaking of capping medication costs, the Virginia Alliance for Medication Access and Affordability (VAMAA) of which we are members continues to work on our “cap the co-pay” legislation. We will be introducing a new bill in the 2016 General Assembly session and are still working on the details. We’ll have more information at our January Advocacy Training and “Richmond Days”.

Our membership in the Healthcare for All Virginians (HAV) Coalition continues. Closing the coverage gap is important for the approximately 40 Virginians who age out of Medicaid each year with no option for purchasing health insurance because of their income status. We have been working with our coalition partners on this effort for the past four years, and we’ll have an uphill slog in the 2016 session. However, we continue to make the case for insurance coverage for all. If you have any questions, don’t hesitate to contact me at becky@B2Lconsulting.com or 804-382-0991.
EXECUTIVE DIRECTOR’S CORNER
Kelly Waters, LCSW, MSW

What a year! 2015 has proven to be one of Virginia Hemophilia Foundation’s (VHF) greatest years of growth. For example, as we closed out the 2014-2015 fiscal year we saw an increase in total assets, had more programming, record attendance, and more geographic program diversity. VHF moved into its first "official" office space in July and welcomed our first social work intern in September.

The NHF Annual Meeting in Dallas, TX was particularly exciting, as we were the recipient of TWO Awards of Distinction for our newly formatted E-newsletter and Teen Retreat. Our scholarship committee was busy awarding the Lyman Fisher Scholarship, Washington Days Scholarship, NHF Annual Meeting Scholarship, and Enrichment Scholarships (Be sure to read more about the scholarship programs and requirements in this issue to see if you might be a fit for one of them).

This has also been a wonderful year for growing our committees, welcoming new volunteers, and exploring new ways to support and enhance our board engagement. Our success would not have been possible without those who donated, volunteered, and participated in our numerous programs. Our close partnerships with our local HTC’s, industry friends, and national organizations (i.e. HFA and NHF) have been tremendously rewarding and appreciated!

As 2015 comes to a close I hope you will consider making a gift to YOUR bleeding disorder organization and/or contacting us about how you would like to help support our mission of providing education, advocacy, and community to those impacted by a bleeding disorder. Thank you for giving of yourself, sharing your valuable resources, and actively participating in the VHF events and programs.

We appreciate you!

GET INVOLVED
UPCOMING EVENTS

Changes to events are possible, call 1-800-266-8438 to confirm event details and visit our website at www.vahemophilia.org/index.php/upcoming-events to learn more or to RSVP.

VHF/HTC Winter Gatherings | December 12
Three gatherings throughout the state with food, fun, education, and holiday treats for all so please come whether you are young or just young at heart...

- **Open to All Members | 10:00 am**
  AMF Kegler’s Lanes | Charlottesville, VA

- **VCU Hemophilia Program | 9:00 am**
  Ramsey United Methodist Church | Richmond, VA

- **Bleeding Disorder Program CHKD | 10:00 am**
  Brickhouse Lobby at CHKD | Norfolk, VA

Educational Dinner | January 7
Fredericksburg | Foode Restaurant at 6:30 pm | Topic will be “Expecting The Unexpected”, Bleeding conditions can impact how you respond to emergencies, such as accidents, trauma, or natural disasters. This program will help you and your family to develop an emergency plan that’s right for you.

Advocacy Training and Richmond Days
January 17 - 18
Richmond | See Article on Page One for More Info

Educational Dinner | January 28
Hampton | Restaurant (TBD) at 6:30 pm | Topic will be “Step It Up!”, a presentation for patients and caregivers that covers the need for those with a bleeding disorder to stay active and meet goals.

Educational Dinner | February 11
Richmond | The Southerly Restaurant at 6:30 pm | Topic will be “Get Off Your Aspirations”, an inspirational presentation targeted for high schoolers through adulthood.

Educational Lunch and Community Event
February 20
Richmond Marriott at 12:00 pm | Topic will be “Healthy Lifestyle” with Speaker Marc Gilgannon and then tickets to the Thunder Nationals Monster Truck Show at the Richmond Coliseum.
EVENT WRAP UP

Educational Dinner | November 3 | Staunton
Heather Conner, Program and Communication Director

VHF members from the western part of the state came out for a night of dinner and education at Emilio’s Restaurant in downtown Staunton. Linda Pollhammer, RN and Clinical Nurse Educator with Pfizer, presented helpful and important information on “Constructive Conversations”. This topic helped both patients and caregivers gain an understanding of how motivational interviewing helps individuals living with bleeding disorders interact with health care providers. Examples of effective conversations were presented which sparked great conversation among our families. Thank you to everyone that came out and thank you to Pfizer for your sponsorship.

Adult Retreat | November 7-8 | Virginia Beach
Sasha Jean-Noel, VHF Social Work Intern

This year’s Adult Retreat took place in Virginia Beach the weekend of November 7-8, 2015. Saturday morning’s workshop, “Your Miracle, Your Life!”, was led by James Stroker and Anita Caronna of Inalex Communications. Through a series of inspiring activities and stories, our members learned new techniques to tell their story, as well as how to enter the next chapter of their life using a fresh perspective.

The workshop was followed by the “Rebuilding the Body with Diet” led by Manny Lopez. During this educational and interactive presentation, Manny informed attendees about the benefits of healthy eating while answering their questions concerning diet and nutrition.

That evening, everyone enjoyed an exciting murder mystery dinner presented by Maverick Theater Productions. The dinner was interactive and provided everyone the opportunity to get to know each other better as they attempted to solve the whodunit mystery. On Sunday morning, Jayla Pricer instructed an all-levels yoga session. Everyone participated in one hour of relaxing meditation and serene yoga poses and stretches. We would like to extend a thank you to our sponsors Baxalta, Drug Co Health, Emergent BioSolutions, Inalex Communications, Novo Nordisk, and the Hemophilia Federation of America.
EVENT WRAP UP

Educational Lunch and Community Event VA Air and Space Center | November 14 | Hampton
Sara Rakestraw, VHF Board of Directors

On Saturday November 14th, 53 members of the bleeding disorders community attended an Educational Lunch and Community Event hosted in Hampton, VA. During lunch, we heard from Marc Gilgannon, a physical therapist at the University of Virginia. Mark led us into an exciting and interactive discussion about nutrition. We all had a great time as we learned how to read our food labels, understand our calorie counts, and much more. We learned that we now can go to www.choosemyplate.gov and learn more great tips and resources about nutrition.

After lunch, we then walked over to the Virginia Air and Space Center. Participants were able to participate in a guided tour or venture out on their own to see all the great exhibits. A great time was had by all! One of the highlights of the day was that we were able to celebrate with Josiah Walker as he turned 13 on this fun day. We joined together as a family and sang a special “Happy Birthday” to Josiah! A special thanks goes out to Drugco Health for supporting this community building event!

Women’s Night Out | November 19 | Richmond
Heather Conner, Program and Communication Director

On a rainy Wednesday evening, VHF brought together over a dozen women from all around central Virginia for a night of food and camaraderie. Speaker, Lori Kunkel, CSL Behring Common Factors Advocate, had everyone in the room laughing through tears as she shared her inspirational life story and her families “habit of laughter” to fend off stress. Then the ladies were supported in finding their inner artist during “Paint Nite! “. And the best part is everyone had their own special Crazy Daisy painting to take home. Special thanks to CSL Behring for sponsoring the event.
SCHOLARSHIPS

VHF is proud to offer many scholarship opportunities for the Virginia bleeding disorders community. All applications and guidelines can be found on our website under the Programs & Services tab. As a reminder, we will NOT have a drawing for the NHF Annual Meeting at this year's VHF Annual Meeting, so don't miss out—Apply today!

National Meetings Scholarship
National Meetings enable our community to come together and exchange information on a wide variety of topics, from the basics of diagnosis to the most relevant developments in treatment and technology. It is the premier opportunity for networking and support for individuals and families affected by bleeding disorders.

Application Deadlines:
- December 15, 2015 for the HFA Symposium in Las Vegas, NV | March 31 - April 2, 2016
- April 1, 2016 for the NHF Annual Meeting in Orlando, FL | July 21 - 23, 2016

VHF Lyman Fisher Scholarship
Deserving members of the VA bleeding disorder community and their families are eligible for a $2000 annual scholarship for secondary or higher education. Two $2000 scholarships are available. Applicants must live in the territorial jurisdiction of VHF and have prior participation with the chapter. Deadline May 1, 2016.

Terry Lamb Enrichment Scholarship
The Terry Lamb Enrichment Scholarship focuses on leadership, volunteerism and/or health promotion. The scholarship can be used for any program (i.e. camp, educational/life skill classes, fitness programs or activities, etc.) that enhances one’s self-esteem, confidence, overall health, leadership skills, areas of interest, development of life skills, and volunteerism. This scholarship is year-round and there is no deadline to apply.

NHF Washington Days Advocacy Event
February 24 - 26, 2016
Meet with your elected officials and make your voice heard on issues that affect you! The scholarship covers registration and hotel expenses. Deadline December 15, 2015.
THE FIRST AND ONLY FACTOR VIII WITH A PROLONGED HALF-LIFE

Learn how a prolonged half-life may affect your infusion schedule

Meet your CoRe Manager Sue Cowell
E: sue.cowell@biogen.com  T: 609-602-6303
This information is not intended to replace discussions with your healthcare provider.

Indications
ELOCTATE [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: control and prevention of bleeding episodes, perioperative management (surgical prophylaxis), and routine prophylaxis to prevent or reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information
Do not use ELOCTATE if you have had an allergic reaction to it in the past.
Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.
Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.
Your body can also make antibodies called, “inhibitors,” against ELOCTATE, which may stop ELOCTATE from working properly.
Common side effects of ELOCTATE are joint pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.
You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of full Prescribing Information on the next page.
FDA-Approved Patient Labeling

Patient Information

ELOCTATE™ /el' ok' tate/
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

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

What is ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?

You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?

Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?

You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?

Common side effects of ELOCTATE are joint pain and general discomfort.

Allergic reactions may occur. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called, “inhibitors,” against ELOCTATE, which may stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
  - Note on the carton the date on which the product is removed from refrigeration.
  - Use the product before the end of this 6 month period or discard it.
  - Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?

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

Manufactured by:
Biogen Idec Inc.
14 Cambridge Center, Cambridge, MA 02142 USA
U.S. License # 1937
44279-01

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Issued June 2014
The Virginia Hemophilia Foundation’s (VHF) Bowling for Bleeding Disorders Fundraiser is scheduled for **Saturday, March 5, 2016 from 2 pm to 4 pm.** There will be two locations: AMF Sunset Lanes in Richmond and AMF Lanes in Chesapeake.

In order to bring awareness and attention to those living with a bleeding disorder VHF scheduled the fundraiser for March because March is Hemophilia Awareness Month. Although the official name only mentions hemophilia, it is intended to bring attention and awareness to all those living with bleeding disorders. We encourage everyone affected by a bleeding disorder to spread the word about Hemophilia Awareness Month by sharing information with their family and friends, and this fundraiser is an excellent opportunity to do so.

This fundraiser is a community event and is an opportunity to give back. Bowling for Bleeding Disorders was developed to raise money to support Camp Youngblood at Camp Holiday Trails. Camp Youngblood is weeklong camp designed to promote fun and learning for children with bleeding disorders, their siblings, and children of those with bleeding disorders at no charge. It costs $600 to send a kid to camp for one week. Help us reach our goal of $35,000 this year by donating money, registering a team, and raising funds.

To register visit the fundraiser website [www.bowlingforbleedingdisorders.myevent.com](http://www.bowlingforbleedingdisorders.myevent.com) and click “Register to Bowl”. Read the instructions carefully and be sure to register for the location you plan on attending. The registration fee for individuals is $25 and the registration fee for teams is $125. This registration fee pays for 2 hours of bowling, shoe rental, t-shirt, food, and great prizes. To guarantee a T-shirt please register and pay by February 22, 2016.

Ready to start fundraising? Once on the website, click on “Start Fundraising” to create a shareable fundraising page. You will be able to create a fundraising page after you have registered either as an individual or as a team. Once you have created your fundraising page, you will be able to promote your profile page online via email and social media to fundraise for this event. Each location has a prize for the top fundraiser—so get started today!

Not able to attend the event, but still want to donate? You can donate to the event in general or to a community members team. All you have to do is go to the website and click on “Donate to a Team”. This page has a participant search bar where you will be able to find the individual or team you are looking to donate to. NOTE – you will still be able to donate to an individual if you use the “Donate to a Team” side bar. If you want to send a donation unaffiliated with an individual or team, click on “General Donations” on the website and follow the form presented.

If you have any questions or concerns about the cost of participating and are interested in fundraising the cost of registration, please contact VHF at 804-740-8643 or admin@vahemophilia.org. Thank you for the support AND happy bowling!
LETTER FROM OUR PRESIDENT
Murai Johnson, VHF Board President

In this season of giving, it’s an excellent time to make plans for the year and your own giving to Virginia Hemophilia Foundation. It is because of you that VHF is able to provide the bleeding disorders community with support through educational and social events, advocacy, women’s programming, empowering teens into leadership, mentoring new families, building relationships and networks within the bleeding disorders community, hemophilia treatment centers and national organizations.

Consider a sustainable gift that is incorporated in your monthly giving to continue our organization’s success in outreach, research and advancement of bleeding disorders. I thank you and hope that you and your family have a safe and happy holiday season. To make a donation visit www.vahemophilia.org and click on the red Donate Now button.

WAYS TO GIVE BACK
To our donors, supporters, corporate sponsors, and volunteers who continue to help us, we are ever so grateful for all you do! Want to know ways you can help? Here are just a few:

- Purchase a Bravelet. Bravelets are bracelets inscribed with the words “be brave”. A full $10 from the purchase of each goes directly to VHF.
- Donate your car, boat, motorcycle, truck or other vehicle to NHF’s Vehicle Donation Program and VHF will receive a portion of the proceeds. Call 1-855-NHF-4-CAR (mention that you would like the proceeds to go to VHF).
- VHF hosts four main fundraising events each year - Bowling for Bleeding Disorders, a Wine Tasting, the Amazing Raise, and the Trick or Trot 5K. We need your help to make these events a success. Please consider attending, serving as a sponsor, volunteering, or donating a toy or raffle item.
- VHF is a member of the Commonwealth of VA Campaign (CVC) If you, your family members, or your friends are state employees, please consider giving (or asking them to give) to VHF through the CVC. Our code is #06043.

Our vision for innovation, brighter than ever.

For more than 60 years, we’ve consistently pursued advancements in the treatment of bleeding conditions.

Now, as Baxter’s BioScience becomes Baxalta Incorporated, this proven heritage—along with the advancements we’re making today to cultivate tomorrow’s developments—fuels our global vision and promise: Our relentless desire to make a meaningful difference in the lives of real people—one person at a time. This promise to you can be seen in all we do, and helps to make us the company we are today.

Baxalta

Victor
Patient, Baltimore, MD

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Virginia Hemophilia Foundation | FACTS N’ FACTORS DECEMBER 2015
CAMP YOUNGBLOOD AT CAMP HOLIDAY TRAILS

Ana Baggiano, CHT Program Director

Camp Holiday Trails (CHT) is proud to partner with the Virginia Hemophilia Foundation (VHF) to offer the following programs in 2016:
- Teen Retreat (April 29 - May 1)
- Family Weekend (May 20 - 22)
- Camp Youngblood (Session 4) (July 24 - 29)

CHT’s Mission - a caring community committed to empowering, encouraging and educating campers with chronic illnesses, their families and healthcare professionals.

At CHT, we strive to create a caring community; with our campers who gain empathy and independence, with our families who find common ground with other families facing similar challenges, and with our network of medical volunteers who are forever changed, both professionally and personally, by their time at camp. Our counselors, teen volunteers, and Horsemanship Program volunteers work directly with our Campers to help them feel better. By feeling supported in a safe environment, Campers engage in many “firsts,” empathize with new friends, and choose to BE better because of their camp experience. One of our campers said “CHT showed me that I did not have a disability, but that I was special. It also gave me a sense of belonging, and to this day provides me with a feeling of hope”. A camper parent wrote, “My children were able to be ‘normal’ enjoying activities such as kayaking, horseback riding, art, swimming, and athletics. Watching them realize that they aren’t the only ones who take meds or have other challenges was the greatest gift”. Our caring community not only supports each other, but also makes sure to have fun together!

CHT is a traditional rustic camp, located in the foothills of the Blue Ridge Mountains in central Virginia. Camps are full of fun programs, which includes activities like: scaling the climbing wall, flying down the zip line, creating messy art projects, shooting a bow and arrow, riding on horseback, fishing with real worms, and canoeing at Waterfront (just to name a few...). All programs are designed to provide safe and exciting opportunities that build self-esteem and confidence, while encouraging positive friendships and community. Campers not only become stronger, more courageous individuals, but they also learn to rely on themselves and others. Camp is a powerfully positive experience. Our campers “choose their challenge” – challenging themselves by making their own decisions and discovering new talents!

Ready for the best summer ever? Apply Now!
You can apply to VHF’s Teen Retreat, Family Weekend, or Camp Youngblood (Session 4), by visiting us on the web at www.campholidaytrails.org. Online applications for Camp Youngblood are DUE on April 30, 2016.

Once you’re on the website, click on the button that says “Apply to Camp” to be redirected to the online camper application. After clicking on the above button, you’ll see a list of guides (i.e. “Camper Application Guide”). Click on the guide that best describes the program you would like to be involved in. If you have any questions that aren’t answered in the guide, we’re here to help! You can contact CHT’s Camp Coordinator, Chris Shifflett, at campisgood@campholidaytrails.org or by calling the camp office at (434) 977-3781, extension 304.

We hope to see YOU at CHT in 2016!
COMING SOON
KOVALTRY™
Antihemophilic factor (recombinant)

Register for updates at
www.KOVALTRY.com

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Bring it and be ready to infuse

XYNTHA® SOLOFUSE brings together proven efficacy and all-in-one reconstitution—in a travel-anywhere kit.

Visit FreeTrialXyntha.com and see if you’re eligible to get a one-time, 1-month supply up to 20,000 IU at no cost.®

What is XYNTHA?

XYNTHA® 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, fainness, 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® SOLOFUSE®.

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, or call 1-800-FDA-1088.

*You must be currently covered by a private (commercial) insurance plan. If you are not eligible for the trial prescription program, you may find help accessing Pfizer medicines by contacting Pfizer’s RxPathways program. For questions about the XYNTHA Trial Prescription Program, please call 1-800-710-1379 or write us at XYNTHA Trial Prescription Program administrator, MedVanx, PO Box 9736, Bloxburg, ID 83717-9736.

®This card is accepted only at participating pharmacies. This card is not health insurance. No membership fee.

Need help accessing Pfizer medicines?
Pfizer’s RxPathways program may be able to help. Call 1-888-327-7787 or visit www.PfizerRxPath.com.

Pfizer RxPathways is a joint program of Pfizer Inc and the Pfizer Patient Assistance Foundation*. 
**Xyntha®**

**Antihemophilic Factor (Recombinant)**

**Xyntha® solofuse**

**Antihemophilic Factor (Recombinant)**

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**Brief Summary**

See package insert for full prescribing information, including patient labeling. For further product information and current patient labeling, please visit XYNTHA.com or call Pfizer Inc toll-free at 1-800-879-5467.

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 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 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
* shortness of breath
* swelling of the face
* 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 IV Use**

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

XYNTHA can last at room temperature (above 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 once 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 or 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 (above 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 syringes. 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 or 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.

The brief summary is based on the Xyntha® (Antihemophilic Factor (Recombinant)) Prescribing Information, LAB-0816-8.0, revised 10/14, and LAB-0950-8.0, revised 10/14.
LISTENING TO THE NEEDS OF WOMEN

Janet Chupka RN, BSN

Originally Published November 17, 2015 on Hemophilia Federation of America’s website: www.hemophiliafed.org/news-stories/2015/11/listening-to-the-needs-of-women/

“Throughout the CHOICE Project we heard from numerous women about their lack of access to the diagnosis and care they need as patients with bleeding disorders. Many women explained that doctors told them women can’t have hemophilia, or a bleeding disorder, and otherwise how providers were dismissive of their symptoms and pain.”

— Wendy Owens, CHOICE Project Officer

That rather disturbing information Wendy gathered was the catalyst for HFA’s Blood Sisterhood program’s “Share Your Story” survey. Unfortunately, it was a consistent and unnerving refrain among the women who took the CHOICE survey: they were having difficulty being seen or receiving treatment for their bleeding disorder symptoms. Some women were even being denied care. This was reported by women utilizing Hemophilia Treatment Centers (HTCs) as well as women who sought medical care elsewhere.

This matter was naturally of great concern to HFA, particularly regarding HTCs. Starting in the fall of 2014, HFA reached out to the Health Resources and Services Administration (HRSA), to ask what requirements HTCs have to care for individuals diagnosed with a bleeding disorder. HRSA is an agency of the US Department of Health and Human Services, and the primary federal agency for improving access to health care and is responsible for the National Hemophilia Program and grant funding that supports HTCs.

HFA also wanted to clarify the needs of women and verify the CHOICE Project feedback. We launched the “Share Your Story” survey on the Blood Sisterhood pages of the HFA website on February 15, 2015. This short, 15-question survey provides women the opportunity to share their experiences in their own words about the care they have received in reaching diagnosis and treatment for their bleeding symptoms.

The following provides a summary of what we learned and what we have done with what we learned in the first six months of the survey collection.

The Data

HFA received 53 completed surveys from women in 26 states across the country. The average age of the women taking the survey was 40 years old, with the youngest being 14 and the oldest 70 years old.

Of the 53 women who completed the survey, five of them reported bleeding symptoms, but did not have a doctor-diagnosed bleeding disorder. The most common symptoms reported were: bruising, heavy menses, post-partum bleeding, nosebleeds and joint pain. Three of the women reported a family history of a bleeding disorder, one had no family history, and one was uncertain whether there was a family history. The other 48 women did report receiving a bleeding disorder diagnosis from a physician.

Of the 48 women with a diagnosis, the following is a breakdown of the type of provider they see for regular care of their bleeding disorder:

- 39 Hematologist
- 5 Family Practice physician
- 5 None

Only 29 women reported receiving any type of treatment for their bleeding disorder. Nineteen of the 48 reported they did not have a treatment plan and do not currently receive any treatment for their diagnosed bleeding disorder.

“My hematologist told me I have moderate hemophilia. He told me I need treatment but he refuses to write the script for factor and tells me to go to the local HTC. My local HTC doctor is one who believes women don’t actually have hemophilia and will not treat a woman. I have bleeds a lot. And a lot of pain. But can’t get treatment.” — Female survey participant

What Did We Hear?

Many women did report receiving a diagnosis, getting good care and following a treatment plan which includes factor. However, others reported care that has been less than adequate and some women reported being refused care altogether. According to these 53 surveys, three women were denied care by local physicians and 10 women reported instances of refusal of care at HTCs across the country simply because they were women.
**What Do Women Want?**
In addition to asking women about their care, HFA also wanted to know what the needs are of the women across the country who experience bleeding disorder symptoms or who have a diagnosis of a bleeding disorder.

We heard overwhelmingly that women want more information and education about bleeding disorders. The majority of the women also stated that provider education specific to women with bleeding disorders is an unquestionable need. Other tools mentioned that women felt would be helpful in managing their bleeding disorders were: HTC uniformity of care, a social media connection, opportunities for social interactions and support.

“I discovered that my hematologist did not believe in female hemophiliacs. I then went to the Mayo Clinic in Rochester, where a hematologist for the very first time called me a hemophiliac. I am not a symptomatic carrier! I am a HEMOPHILIAC! I am routinely referred to as a symptomatic carrier by my local hematologists.” — Female survey participant

**What is HFA doing?**
We have reported to HRSA all 10 of the instances where an alleged denial of care to women occurred at HTCs.

HRSA has been receptive to this information and will be working with their Regional Coordinators on this issue.

Some of the women who took the survey found insurance issues to be an additional barrier to receiving quality care. Organizationally, we have created Project CALLS (Creative Alternatives to Limiting and Lacking Services). Project CALLS is an opportunity for the community to share their experiences with insurance issues while helping the entire bleeding disorders community. Through Project CALLS, HFA will collect stories from the bleeding disorders community across the country, collate the data, identify trends, and use the information to build a case for changes in the insurance industry.

Programmatically, HFA’s Blood Sisterhood program will continue to provide the education, support, and resources that women need to reach a diagnosis, and continue that support through the stages of their lives with a bleeding disorder. In 2015 we had 20+ local educational sessions of Blood Sisterhood happening at our local member organizations, as well as webinars, an improved website information for women, and a mobile app that allows women to track their menstrual cycles and bleeds and share that information with their health care provider. We have added a new physician, Robert Sidonio, MD, MSc, as a medical advisor to our professional advisors team. Dr. Sidonio is passionate about addressing the needs of women with bleeding disorders.”

We also are partnering with other organizations to raise awareness, particularly those that provide education and training to health care providers such as the Foundation for Women and Girls with Blood Disorders.

“I have repeatedly been told, ‘you are just mild’ even when having bad issues. I feel like they don’t listen to me or my concerns. I wish they would treat the symptoms and person, not how the labs read.” — Female survey participant

**Looking Ahead**
HFA plans to continue the “Share Your Story” survey and learn from women across the country over the next year. A more detailed report of the first year will be available in the spring of 2016.

We will also continue listening to women and collecting their stories through this survey and other means about the health care they are receiving. We will persevere in reporting to HRSA about women with a diagnosis who have been refused care at HTCs, as we continue to seek our overall objective of assisting women and raising a united voice for positive change that is felt by the women in our community.
ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indication
ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Detailed Important Risk Information
You should not use ADYNOVATE if you:
- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE (Antihemophilic Factor [Recombinant])

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

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 mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body’s normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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

Please see following page for ADYNOVATE Important Facts.

For full Prescribing Information visit www.ADYNOVATE.com.

**ADYNOVATE**

**[Antihemophilic Factor (Recombinant), PEGylated]**

**Important facts about**

**ADYNOVATE** [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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**What is the most important information I need to know about ADYNOVATE?**

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

---

**What is ADYNOVATE?**

ADYNOVATE is an injectable medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

---

**Who should not use ADYNOVATE?**

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE

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

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**How should I use ADYNOVATE?**

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider’s office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

---

**What are the possible side effects of ADYNOVATE?**

You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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

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**What else should I know about ADYNOVATE and Hemophilia A?**

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body’s normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about ADYNOVATE. The FDA approved product labeling can be found at www.Adynovate.com or 855-4-ADYNATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
DONOR THANK YOU

Listed below are individuals and organizations who have made a financial contribution from August 1, 2015 to November 5, 2015. The Virginia Hemophilia Foundation is so grateful to you all.

If we inadvertently omitted or misspelled your name, please accept our most sincere apologies.

ORGANIZATIONAL

- AHF, Inc.
- Baxalta
- Bayer HealthCare
- Bravelets
- Commonwealth Energy Systems
- Community Health Charities Of VA
- CSL Behring
- DrugCo Health
- Emergent BioSolutions
- Hemophilia Federation Of America, Inc.
- National Hemophilia Foundation
- Novo Nordisk
- Superior Biologics

INDIVIDUALS

- Adams, Sabrina
- Anonymous
- Arrington, Robyn
- Arzadum, Virginia
- Bailey, Nicole
- Banton, Michelle
- Barber, Alison
- Barker, Benjamin
- Bartko, Myron and Kathleen
- Becker, Sara
- Beers, Dana
- Bordone, Donna
- Bordone, Zack
- Bowen, Alyssa
- Bowers-Lanier, Becky
- Bunn, William and Heather
- Calfee, Christopher
- Cartwright, Kelly Branam
- Chapman, Jason
- Collins, T Patrick
- Conner, Heather
- Derbyshire, Matt
- Dunn, Lauren
- Eiden, Thomas
- Eiden, Thomas J.
- Fuller, Ernestine
- George, Eric
- Gilgannon, Marc
- Grant, Sarah
- Harmeling, Fredrick
- Hartsfield, Justin and Ava
- Herin, Steven and Renee
- Herring, Jeff and Michelle
- Hess, Andrea
- Heuple, Rhonda
- Hughes, Charles and Audra
- Johnson, Murai
- Krecak Family
- Larson, Michael
- Lawson, Megan
- Leftwich, Beth
- Massey, Gita
- Maurer, Jeffrey
- McFadden, Patricia
- Melton, Aidan and Valerie
- Midura, Megan
- Miller, Rachel
- Moore, Bryan
- Moore, Claire
- Moore, Sharon
- Mortimer, Kathy
- Mustak, Silvana
- Noble, Stacey
- Nolte, Paul and Mindy
- Norris, Pamela
- O’Connor, Kevin
- Parker, Amy
- Parnell, Jean
- Peterson, Jana
- Pope, Mary
- Porche, Schuyler and Kaui
- Rakestraw, Sara
- Raymond, Gina
- Recknor, Shirley "Kay" and Robert "Bob"
- Shaw, Lynda
- Slusher, Carol
- Smith, Donald and Beth
- Smoak, Shelby
- Stiefvater, Jodi and Allison
- Talmadge, Kelsey
- Valentino, Al
- Vaughan, Allison
- Walker Family
- Warren, Daniel
- Waters, Kelly
- Welshonce, Jeff and Debbie
- Welshonce, Michael
- Williford, Deborah
- Wilson, Randy and Marti
- Winstead, Faith
- Zeak, Nicole

Special recognition and thank you to VHF Board Secretary, Monika Eiden. She brought in over $900 in donations for our Trick or Trot 5K Fundraiser. Thanks again Monika and thank you to your generous friends and family!
**FIND YOUR LOCAL HTC**

**Bleeding Disorders Center of Hampton Roads**  
Children's Hospital of the King's Daughters (CHKD)  
Division of Hematology/Oncology  
601 Children's Lane  
Norfolk, VA 23507

Gary Woods, MD, Pediatric Bleeding Disorder  
Medical Director  
Contact: Kim Stewart, BSN  
Phone: 757-668-7613  
Email: kstewart@chkd.com

**University of Virginia Division of Pediatric Hematology & Oncology**  
4th Floor, Primary Care Center  
UVA Medical Center  
1221 Lee Street  
Charlottesville, VA 22908

Kimberly Dunsmore, MD, Pediatric Medical Director  
Contact: Margy Sennett, PNP  
Phone: 434-924-8499  
Email: mms9D@virginia.edu

**Central Virginia Center for Coagulation Disorders**  
VCU Health Systems  
1200 E. Broad Street, Room 442  
Richmond, VA 23298

J. Christian Barrett, MD, Adult Medical Director  
Gita V Massey, MD, Pediatric Medical Director  
Contact: Jan Kuhn, RN, MPH  
Phone: 804-827-3306  
Email: jgkuhn@hsc.vcu.edu

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**VOLUNTEER THANK YOU**

We would like to thank all the individuals who volunteered their time and energy in 2015 - we couldn’t do what we do without you!

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**Trust the Experience**

At CVS/specialty, we’ve been helping families like yours for over 30 years. Our caring patient support helps ensure safety, convenient access and satisfaction.  
[www.CVSSpecialty.com](http://www.CVSSpecialty.com)

**April Owens**, Client Relations Executive  
Mid-Atlantic Region  
(Hemophilia/VwD/IVIG Specialty Services)  
april.owens@cvsaremark.com  
202-615-1262

**Craig Voorhees**, Northeast Regional Sales Manager  
(Hemophilia/VwD/IVIG Specialty Services)  
craig.voorhees@cvsaremark.com  
860-885-8085

**Pharmacy**  
1127 Bryn Mawr Avenue  
Redlands, CA 92374  
800-541-2934 (toll-free for 24/7 support)  
909-799-6462 (fax)
Indications and Usage
NUWIQ is a Recombinant Antihemophilic Factor (blood coagulation factor VIII (Factor VIII)) indicated in adults and children with Hemophilia A for on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and for routine prophylaxis to reduce the frequency of bleeding episodes. NUWIQ is not indicated for the treatment of von Willebrand Disease.

Important Safety Information
NUWIQ is contraindicated in patients who have manifested life-threatening hypersensitivity reactions, including anaphylaxis, to the product or its components. The most frequently occurring adverse reactions (>0.5%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, non-neutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth. Development of Factor VIII neutralizing antibodies (inhibitors) may occur.

Please see adjacent page for Brief Summary of Prescribing Information.
HIGHLIGHTS OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use NUWIQ safely and effectively. See full prescribing information for NUWIQ.

NUWIQ®, Anthemophilic Factor (Recombinant) Lyophilized Powder for Solution for Intravenous Injection
Initial U.S. Approval: 2015

INDICATIONS AND USAGE
NUWIQ is a recombinant antihemophilic factor (FVIII) product indicated in adults and children with Hemophilia A for:
• On-demand treatment and control of bleeding episodes
• Perioperative management of bleeding
• Routine prophylaxis to reduce the frequency of bleeding episodes
NUWIQ is not indicated for the treatment of von Willebrand Disease.

DOSE AND ADMINISTRATION
For intravenous use after reconstitution
• Each vial of NUWIQ is labeled with the actual amount of Factor VIII potency in international units (IU).
• Determine dose using the following formula for adolescents and adults:
  Required IU = body weight (kg) x desired Factor VIII rise (%) x 0.5 (IU/kg per IU/mL)
• Dosing for routine prophylaxis:

<table>
<thead>
<tr>
<th>Subjects</th>
<th>Dose (IU/kg)</th>
<th>Frequency of infusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescents [12-17 yrs] and adults</td>
<td>30-40</td>
<td>Every other day</td>
</tr>
<tr>
<td>Children [2-11 yrs]</td>
<td>30-50</td>
<td>Every other day or three times per week</td>
</tr>
</tbody>
</table>

• Frequency and duration of therapy depends on severity of the FVIII deficiency, location and extent of bleeding, and patient’s clinical condition.

DOSE FORMS AND STRENGTHS
NUWIQ is available as a sterile, non-pyrogenic, lyophilized powder for reconstitution in single-use vials containing nominally 250, 500, 1000 or 2000 IU Factor VIII potency.

CONTRAINDICATIONS
NUWIQ is contraindicated in patients who have manifested life-threatening hypersensitivity reactions, including anaphylaxis, to the product or its components.

WARNINGS AND PRECAUTIONS
• Hypersensitivity reactions, including anaphylaxis, are possible. Should symptoms occur, discontinue NUWIQ and administer appropriate treatment.
• Development of Factor VIII neutralizing antibodies (inhibitors) may occur. If expected plasma Factor VIII activity levels are not attained, or if bleeding is not controlled with an appropriate dose, perform an assay that measures Factor VIII inhibitor concentration.
• Monitor all patients for Factor VIII activity and development of Factor VIII inhibitor antibodies.

ADVERSE REACTIONS
The most frequently occurring adverse reactions (>0.5%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, non-neutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth.

USE IN SPECIFIC POPULATIONS
Pediatric Use: Lower recovery, shorter half life and faster clearance in children aged 2 - <12 years. Higher doses and/or a more frequent dosing schedule for prophylactic treatment should be considered in pediatric patients aged 2 to 5 years.

PATIENT COUNSELING INFORMATION
Advise patients to read the FDA-approved patient labeling (Patient Information and Instructions for Use).

Because hypersensitivity reactions are possible with NUWIQ, inform patients of the early signs of hypersensitivity reactions, including hives, generalized urticaria, tightness of the chest, wheezing, hypotension, and anaphylaxis. Advise patients to seek medical treatment if any of these symptoms arise and contact their physician, and seek prompt emergency treatment.

Advise patients to contact their physician or treatment center for further treatment and/or assessment if they experience a lack of clinical response to Factor VIII replacement therapy, as this may be a manifestation of an inhibitor.

Advise patients to consult with their healthcare provider prior to traveling. While traveling, patients should be advised to bring an adequate supply of NUWIQ based on their current treatment regimen.

To report SUSPECTED ADVERSE REACTIONS, contact Octapharma USA Inc. at 1-866-766-4860 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

Manufactured by:
Octapharma AB
ELOWÄNGE 40
SE-112 75, Sweden
U.S. License No. 1646

Distributed by:
Octapharma USA, Inc.
121 River Street, Suite 1201
Hoboken, NJ 07030

NUWIQ is a registered trademark of Octapharma. Issued September 2015.

Revised September 2015

For all inquiries relating to drug safety, or to report adverse events please contact our local Drug Safety Officer:
Office: 201-604-1137 | Cell: 201-772-4546 | Fax: 201-604-1141

Virginia Hemophilia Foundation | FACTS N’ FACTORS DECEMBER 2015
Thank you to everyone that came out to celebrate our new space! Don’t forget to update your address book (if you have not already) to our new location: 410 N. Ridge Rd., Suite 215, Richmond, VA 23229.

This year's Meeting will be held in Orlando, FL at the Gaylord Palms Resort & Convention Center. This venue is just minutes away from Disney World, Magic Kingdom, Universal Studios, SeaWorld, and more! Join NHF for three days full of educational sessions, networking opportunities, and access to the exhibit hall. All registrations include entrance to the Opening Session, Opening Reception, Awards Ceremony, and Final Night event. Childcare is offered for children under 17 years old. Early Registration rates will be available until January 22, 2016.
Virginia Hemophilia Foundation
410 N. Ridge Rd., Suite 215 | Richmond, VA 23229
800-266-8438 or 804-740-8643 | www.vahemophilia.org

VHF 2016 Calendar Changes to the calendar are possible, call 1-800-266-8438 to confirm event details.

January
- January 7 – Educational Dinner (Fredericksburg)
- January 17-18 – Advocacy Training and Richmond Days (Richmond)
- January 28 – Educational Dinner (Hampton Roads/Tidewater)

February
- February 11 – Educational Dinner (Richmond)
- February 20 – Educational Lunch and Community Event – Monster Truck Show (Richmond)

March
- Hemophilia Awareness Month
  - March 5 – Winter Fundraiser – Bowling For Bleeding Disorders Bowl-a-thon (Richmond and Chesapeake)
  - March (TBD) – Educational Dinner (Western Region)
  - March 16 – Women’s Night Out (Hampton Roads/Tidewater)
  - March 19 – Dads in Action (Hampton Roads/Tidewater)
  - March 31 – April 3 – HFA Symposium (Las Vegas)

April
- April 1 – VHF Scholarship Application for NHF Annual Meeting Due
- April 7 – Educational Dinner (Hampton Roads/Tidewater)
- April 8 – First Step (Norfolk)
- April 17 – Blood Brotherhood Event/World Hemophilia Day (Richmond)
- April 24 – Spring Fundraiser - Wine Tasting and Silent Auction (Richmond)
- April 29 – May 1 – Teen Retreat at Camp Holiday Trails (Charlottesville)
- April 30 – Camp Youngblood Online Application Due

May
- May 1 – Lyman Fisher Scholarship Application Due
- May 5 – Educational Dinner (Roanoke)
- May 14 – Celebrate Spring Community Event (Western Region)
- May 20-22 – Family Weekend at Camp Holiday Trails (Charlottesville)
- (TBD) Educational Dinner (TBD)
- (TBD) Batter Up Event (Norfolk)

June
- June 4 – Women’s Day Out (Roanoke)
- June 17 - 18 – Annual Education Meeting (Charlottesville)
- June 30 – Educational Dinner (Winchester)

July
- July 21-23 – NHF Annual Meeting (Orlando)/July 24-28 – World Hemophilia Foundation Meeting (Orlando)
- July 24-29 – Camp Youngblood at Camp Holiday Trails (Charlottesville)

August
- August (TBD) – Educational Dinner (TBD)
- August 6 – Teen Weekend (Richmond)
- August 7 – Celebrate Summer Community Event (Richmond)
- August 27 – Back To School Picnic (Virginia Beach)

September
- September 14 – Educational Dinner (Richmond)
- September 14-15 – Amazing Raise (Online Fundraiser)
- September 24-25 – Family Retreat at Great Wolf Lodge (Williamsburg)
- September (TBD) – Educational Dinner (Western Region)

October
- October 6 – Educational Dinner (Hampton Roads/Tidewater)
- October 8-9 – Adult Retreat (Staunton)
- October 15 – Celebrate Fall Community Event (Shenandoah Region)
- October 29 – Fall Fundraiser - Trick or Trot 5K and Monster Dash (Midlothian)

November
- November 3 – Women’s Night Out (Richmond)
- November (TBD) – Educational Dinner (Western Region)
- November 12 – Educational Lunch and Community Event (Hampton Roads/Tidewater)

December
- December 1 – Educational Dinner and Celebrate Winter Community Event (Hampton Roads/Tidewater)
- December 10 – Winter Gatherings (Charlottesville, Norfolk, Richmond)
Our enduring commitment, brighter than ever.

**For more than 60 years, we’ve consistently pursued advancements in the treatment of bleeding conditions.**

Now, as Baxter’s BioScience becomes Baxalta Incorporated, this proven heritage — along with the advancements we’re making today to cultivate tomorrow’s developments — fuels our global vision and promise: Our relentless desire to make a meaningful difference in the lives of real people — one person at a time. This promise to you can be seen in all we do, and helps to make us the company we are today.

Miriam
Caregiver, Miami, FL

- Baxter is a trademark of Baxter International Inc.
- Baxalta is a trademark of Baxalta Incorporated.
- Used with permission. For information: June 2015 U.S./Aug. 75–0181.
Open Enrollment starts November 1, 2015! To help you get started, answer the following questions to help you choose the right plan for you and your family:

☑ Is the plan right for your budget? Can you afford the monthly premiums and annual deductible?
☑ Does the plan include your doctor, hospital, or clinic of choice?
☑ Do you have medications that need to be covered?
☑ What are your healthcare needs? Do you have a health condition or expect any major health expenses?
☑ If you already have a plan, do you like it?
☑ How does your plan compare to other plans on the Marketplace?
☑ Is there a plan that provides even better coverage, including prescription drugs?
☑ Do you have any life changes you need to report, such as change in your income, address, or even family size?

To help you answer these questions and make the best choice, 2016 health insurance plans are required to provide even more information. You will be able to:

- View a complete and accurate doctor or provider directory. (Call your doctor to confirm!)
- See if the doctor or provider is accepting new patients.
- Obtain the doctor or provider’s contact information, location, and hospital/clinic.
- View a complete and accurate list of all covered drugs.
- See a full list of benefits in your health plan package.
- Understand your rights, including how to file an appeal or grievance.
- Receive instructions on how to make appointments and get benefits.

Help is available! For more information about picking a plan, go to:

Healthcare.gov (Marketplace) at www.healthcare.gov
Phone: 1-800-318-2596 TTY: 1-855-889-4325 Spanish: 1-800-318-2596

For in-person assistance, contact Enroll Virginia at www.enrollva.org
or call 1-866-659-7474.
**INSURANCE OPTIONS**

Instructions: Use the chart below to compare different health plans. Your monthly premium and overall costs should include tax credits and other cost savings based on your income.

---

2016 Estimated Income ________________   Premium Tax Credit (PTC) $ ______________ (Monthly)

<table>
<thead>
<tr>
<th>Insurance Company</th>
<th>Current Plan</th>
<th>Option 1</th>
<th>Option 2</th>
<th>Option 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Plan Name</strong></td>
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<td>Type of Plan (HMO, POS, PPO)</td>
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<td>Metal Tier (Bronze, Silver, Gold, Platinum)</td>
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<td><strong>Copays/Coinurance (% of Cost)</strong></td>
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<td>Specialist Visit</td>
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<td><strong>Cost of Services</strong></td>
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<tr>
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<td>Current Prescription Drugs</td>
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“This project is supported by the U.S. Department of Health and Human Services, FOA CA-NAV-15-001 from CMS. The contents provided are solely the responsibility of the authors and do not necessarily represent the official views of HHS or any of its agencies.”