Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Summer 2015
Inside this issue

Come for the RUN and Stay for the FUN!

Run For Their Lives 5K & Hemophilia Walk

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DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

If your company is participating in the United Way campaign, you may designate all or a portion of your gift to the Chapter.

WPCNHF Contributor Agency Code Number is: **83**

FOOD & FITNESS BASICS

On April 27, we offered a new program to our members: Food & Fitness Basics, followed by a cooking demonstration and dinner! This program was held in Robinson Township at the Giant Eagle Market District and was sponsored by Novo Nordisk.

The program began with an overview on Food & Fitness Basics, by Cathy Tiggs, Social Worker at University Hospital in Cleveland. The program included the benefits of physical activity and good nutrition, guidelines for choosing physical activities and exercises, how to read food labels and make healthy choices, and how small changes may help lead to a healthier life style. After an interactive discussion, Cathy left us with tools for setting and tracking goals.

Next, we moved into the Giant Eagle Market District Cooking School and were treated to a cooking demonstration and a delicious meal! The chefs shared tips as they prepared each recipe and welcomed all of our questions. Chef Alexandria Kwoke, Giant Eagle Market District Cooking School has shared the following recipe from the evening with you:

Aprihop Apricot Arugula Salad with Goat Cheese
Serves: 4 • Prep Time: 15 minutes

Ingredients:
8 oz Arugula
Crumbled Goat Cheese, as needed
Slivered Almonds, garnish
Endive
Dressing:
1 Shallot, fine mince (about a teaspoon, unless you like more)
1 Garlic clove, fine mince
2 teaspoons Honey
½ cup dried Apricots, thinly sliced, split (see instructions)
1 ¼ cup Dog Fish Head Aprihop, split (see instructions)
¼ cup Sugar
¾ cup Grape seed oil

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LIVING FIT WITH VON WILLEBRAND DISEASE

This piece was originally published by the Hemophilia Federation of America (HFA) in May of 2015. We are re-publishing with permission from HFA.

One of the most common bleeding disorders in women is von Willebrand Disease (vWD), which occurs in about 1% of the US population. Heavy bleeding is one of the most common problems women report to their doctors. It affects more than 10 million American women each year. This means that about one out of every five women has heavy menstrual bleeding. Women often live with

(Continued on page 7)

RUN FOR THEIR LIVES

Bleeding disorders can't stop us.

HIT THE GROUND RUNNING!

Saturday, September 12, 2015

Location: North Park/Harmar Grove Shelter
Allison Park, PA
Registration: 7:30am
Race Start Time: 8:30am
Race Distance: 5K

An expected 150+ Western Pennsylvanians will hit the ground running to raise money for the Western Pennsylvania Chapter of the National Hemophilia Foundation in the 6th Annual Run For Their Lives 5K!

WPCNHF has once again partnered with Elite Runners! **Register today at www.wpcnhf.org/event/run**

COME FOR THE RUN AND STAY FOR THE FUN!

National Hemophilia Foundation and Western Pennsylvania Chapter of NHF Present

HEMOPHILIA walk '15 SM

Every step makes a difference

National Presenting Sponsor
Baxter

Registration: 9:00am
Walk Start Time: 10:00am
Walk Distance: 5K

Join us for the **7th Annual Western Pennsylvania Hemophilia Walk!** We will walk to raise critical **FUNDS** and **AWARENESS** for the bleeding disorders community. The event will include entertainment for the entire family. All proceeds **stay local** to benefit WPCNHF! Register your team today!

For more information, please visit, www.hemophilia.org/walk and click on PA or contact Kara Dornish, Marketing and Events Manager, by phone 724-741-6160 or email kara@wpcnhf.org.

Letter From The President, Scott Miller

Dear Chapter Members and Stakeholders,

Summer is here! While summer activities are just beginning, the chapter has been hard at work developing programs and advocating for our members. Already in 2015, we had infusion day, a very successful teen retreat, and programing for men and women. Our annual Harrisburg Days advocacy trip produced some good results and relationships with newer legislators and it was great to see new faces at the event this year!

You know it is summer when we start talking about Camp! Camp Hot-to-Clot was a success and I want to thank all that participated in making that a success – a big shout out to the camp Planning Committee who, along with all of the volunteers, did a wonderful job!

The Chapter staff and board continue to plan events for our members that will be current and relevant and have an impact on your lives. We continue to find segments of our membership that are in need of services and develop programs to meet those needs. The responsiveness of the participants, sponsors, presenters, and staff continues to be strong, allowing our members to continue to have access to high quality programming as well as opportunities to have good conversation about issues we face and successes we experience.

As we begin our summers, please remember to mark your calendars for the Annual Meeting on July 23rd in Homestead. If you have not done so already, be sure to register your team for the Annual Hemophilia Walk and encourage your family and friends to take part in the Walk as well as Run for Their Lives®, both on September 12, 2015. These events continue to be among our most important fundraisers that allow us to provide the programming and services our members want and need as we implement our new mission and strategic plan.

As always, I want to THANK YOU for your continued support of the Chapter and remind you that you are free to contact us if we can be of service or if you need assistance. I look forward to seeing you all at the Annual Meeting!

Sincerely,

Scott E. Miller, CPA, J.D., DBA
WPCNHF Board President

Letter From The Executive Director, Alison Yazer

Dear Chapter Members and Friends,

I hope that the arrival of our summer newsletter finds you and your family well. The Chapter continues to work toward increasing both the number and locations of our educational programs and I hope you plan to join us for some of these great upcoming events.

Our first ever Teen & Parent Retreat took place in March and proved to be a huge success! Members heard speakers on a variety of topics and a good time was had by all. We appreciate everyone involved in helping to plan and participate in this event.

Included in this issue are a variety of articles and invitations that will help you and your family. Each item included in this newsletter, along with the myriad of education programs we plan for you, provides a great opportunity for you to learn more about your bleeding disorder.

I hope you are planning to join us for the Chapter's Annual Meeting and Walk Kickoff on Thursday, July 23rd at Dave & Buster's in Homestead. Our manufacturing partners will each have a few minutes to talk about their companies and products so this event will be incredibly informative as well as fun!

As always, please contact the staff of WPCNHF with any suggestions, questions or concerns. Thank you for all that you do on behalf of the bleeding disorders community. On behalf of the staff of WPCNHF, I wish you a safe and happy summer!

Sincerely,

Alison R. Yazer
Executive Director

Amish Outreach

As part of the Chapter's dedication to bring programs to more communities in our region, we have begun to offer a series of educational programs, exclusively for Amish members. Our first stop was Punxsutawney, in April, and due to popular demand, we will be returning this summer! The first topic we offered was Hemophilia Basics, which was presented by Nayan Heath, a nurse educator, with Pfizer, Inc. In the fall, we will expand our program into other Amish communities, as well as offer additional topics.

Calendar of Upcoming Events

Wednesday, July 15
Hemophilia Overview – Amish Only
Punxsutawney, PA

Thursday, July 23
WPCNHF Annual Meeting
Plus Exhibit Displays
Homestead, PA

Saturday, August 1
Program for Female Caregivers
Pittsburgh, PA

Thursday, August 13 – Saturday, August 15
NHF Annual Meeting
Dallas, TX

Saturday, August 29
Cracking the Code and Power of Empowerment
Plus Exhibit Displays
Erie, PA

Saturday, August 29
Waldameer Park
Erie, PA

Saturday, September 12
Hemophilia Walk
North Park, Allison Park, PA

Saturday, September 12
Run For Their Lives 5K™
North Park, Allison Park, PA

Saturday, October 24
Self-Advocacy
Plus Exhibit Displays
Ligonier, PA

Friday, November 20 – Sunday, November 22
Take A Bough™
Pittsburgh, PA

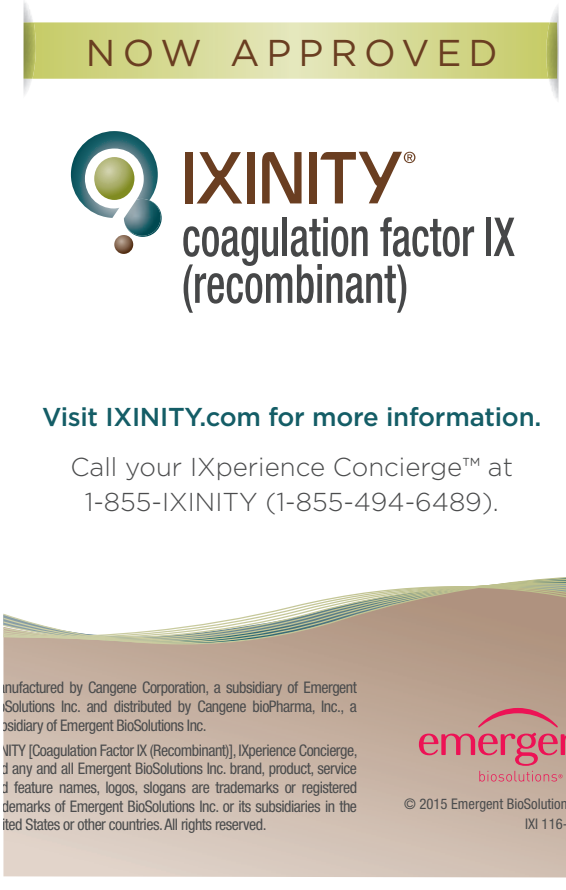
Saturday, December 5
Winterfest
Wheeling, WV

CFC® Combined Federal Campaign

Combined Federal Campaign

WPCNHF is an approved charitable organization for the Combined Federal Campaign (CFC). If you participate in the CFC, please consider designating all or a portion of your donation to the Chapter.

WPCNHF CFC Number is: 81343



Ask us about sponsorship opportunities and how you can help!

UNLOCKING YOUR SELF-POTENTIAL

ADVATE
[Antihemophilic Factor (Recombinant)]
There's more to life.

ADVATE HAS A PROVEN SAFETY PROFILE[1-7]

Low risk of inhibitor development in previously treated patients (PTPs) demonstrated in clinical studies[1-5]

(95% confidence interval, 0.02%–2.13%)

6 CLINICAL STUDIES / **270** PATIENTS WITH MODERATELY SEVERE TO SEVERE HEMOPHILIA A

- **1 low-titer, nonpersistent inhibitor (<1%)** in a pivotal study*†[3] (n=108)
- **0 inhibitors** in a continuation study*†[2] (n=82); a pediatric study‡[5] (n=53); a surgery study*†[4] (n=59); a Japanese study[2] (n=15); and a prophylaxis study*§[1] (n=73)

*Patients with an estimated ≥150 factor VIII exposure days.[1,3,4]
†Some patients participated in more than 1 study.[2]
‡Patients with an estimated ≥50 factor VIII exposure days.[5]
§There was 1 case of a possible low-titer factor VIII inhibitor, which was unconfirmed, unaccompanied by symptoms of inhibitor presence, and disappeared at the subject's subsequent test.[1]

ADVATE [Antihemophilic Factor (Recombinant)] Important Information

Indications

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.
Your healthcare provider may give you ADVATE when you have surgery.
ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADVATE if you:
- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE 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 ADVATE 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 ADVATE 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 ADVATE.

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.

Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash.

Tell your healthcare provider about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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 Brief Summary of ADVATE full Prescribing Information.

References: 1. Valentino LA, Mamonov V, Hellmann A, et al. A randomized comparison of two prophylaxis regimens and a paired comparison of on-demand and prophylaxis treatments in hemophilia A management [published correction appears in *J Thromb Haemost*. 2012;10(6):1204]. *J Thromb Haemost*. 2012;10(3):359-367. **2.** Shapiro A, Gruppo R, Pabinger I, et al. Integrated analysis of safety and efficacy of a plasma- and albumin-free recombinant factor VIII (rAHF-PFM) from six clinical studies in patients with hemophilia A. *Expert Opin Biol Ther*. 2009;9(3):273-283. **3.** Tarantino MD, Collins PW, Hay CRM, et al, and the rAHF-PFM Clinical Study Group. Clinical evaluation of an advanced category antihaemophilic factor prepared using a plasma/albumin-free method: pharmacokinetics, efficacy, and safety in previously treated patients with haemophilia A. *Haemophilia*. 2004;10(5):428-437. **4.** Négrier C, Shapiro A, Berntorp E, et al. Surgical evaluation of a recombinant factor VIII prepared using a plasma/albumin-free method: efficacy and safety of Advate in previously treated patients. *Thromb Haemost*. 2008;100(2):217-223. **5.** Blanchette VS, Shapiro AD, Liesner RJ, et al, for the rAHF-PFM Clinical Study Group. Plasma and albumin-free recombinant factor VIII: pharmacokinetics, efficacy and safety in previously treated pediatric patients. *J Thromb Haemost*. 2008;6(8):1319-1326. **6.** Oldenburg J, Goudemand J, Valentino L, et al. Postauthorization safety surveillance of ADVATE [antihaemophilic factor (recombinant), plasma/albumin-free method] demonstrates efficacy, safety and low-risk for immunogenicity in routine clinical practice. *Haemophilia*. 2010;16(6):866-877. **7.** Auerswald G, Thompson AA, Recht M, et al. Experience of Advate rAHF-PFM in previously untreated patients and minimally treated patients with haemophilia A. *Thromb Haemost*. 2012;107(6):1072-1082.

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ADVATE [Antihemophilic Factor (Recombinant)]
Lyophilized Powder for Reconstitution for Intravenous Injection
Brief Summary of Prescribing Information: Please see package insert for full Prescribing Information.

INDICATIONS AND USAGE

ADVATE [Antihemophilic Factor (Recombinant)] is a recombinant antihemophilic factor indicated for use in children and adults with hemophilia A (congenital factor VIII deficiency or classic hemophilia) for:

- Control and prevention of bleeding episodes.
- Perioperative management.
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

ADVATE is not indicated for the treatment of von Willebrand disease.

CONTRAINDICATIONS

ADVATE is contraindicated in patients who have life-threatening hypersensitivity reactions, including anaphylaxis, to mouse or hamster protein or other constituents of the product (mannitol, trehalose, sodium chloride, histidine, Tris, calcium chloride, polysorbate 80, and/or glutathione).

WARNINGS AND PRECAUTIONS

Hypersensitivity Reactions

Allergic-type hypersensitivity reactions, including anaphylaxis, have been reported with ADVATE. Symptoms include dizziness, paresthesia, rash, flushing, facial swelling, urticaria, dyspnea, and pruritus.

ADVATE contains trace amounts of mouse immunoglobulin G (MuIgG) ≤0.1 ng/IU ADVATE, and hamster proteins ≤1.5 ng/IU ADVATE. Patients treated with this product may develop hypersensitivity to these non-human mammalian proteins.

Discontinue ADVATE if hypersensitivity symptoms occur and administer appropriate emergency treatment.

Neutralizing Antibodies

Neutralizing antibodies (inhibitors) have been reported following administration of ADVATE predominantly in previously untreated patients (PUPs) and previously minimally treated patients (MTPs). Monitor all patients for the development of factor VIII inhibitors by appropriate clinical observation and laboratory testing. If expected plasma factor VIII activity levels are not attained, or if bleeding is not controlled with an expected dose, perform an assay that measures factor VIII inhibitor concentration. [see *Warnings and Precautions*]

Monitoring Laboratory Tests

- Monitor plasma factor VIII activity levels by the one-stage clotting assay to confirm the adequate factor VIII levels have been achieved and maintained when clinically indicated. [see *Dosage and Administration*]
- Perform the Bethesda assay to determine if factor VIII inhibitor is present. If expected factor VIII activity plasma levels are not attained, or if bleeding is not controlled with the expected dose of ADVATE, use Bethesda Units (BU) to titer inhibitors.
  - If the inhibitor titer is less than 10 BU per mL, the administration of additional antihemophilic factor concentrate may neutralize the inhibitor and may permit an appropriate hemostatic response.
  - If the inhibitor titer is above 10 BU per mL, adequate hemostasis may not be achieved. The inhibitor titer may rise following ADVATE infusion as a result of an anamnestic response to factor VIII. The treatment or prevention of bleeding in such patients requires the use of alternative therapeutic approaches and agents.

ADVERSE REACTIONS

The serious adverse reactions seen with ADVATE are hypersensitivity reactions and the development of high-titer inhibitors necessitating alternative treatments to factor VIII.

The most common adverse reactions observed in clinical trials (frequency ≥10% of subjects) were pyrexia, headache, cough, nasopharyngitis, vomiting, arthralgia, and limb injury.

Clinical Trial Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in clinical trials of another drug and may not reflect the rates observed in clinical practice.

ADVATE has been evaluated in five completed clinical trials in previously treated patients (PTPs) and one ongoing trial in previously untreated patients (PUPs) with severe to moderately severe hemophilia A (factor VIII ≤2% of normal). A total of 234 subjects have been treated with ADVATE as of March 2006. Total exposure to ADVATE was 44,926 infusions. The median duration of participation per subject was 370.5 (range: 1 to 1,256) days and the median number of exposure days to ADVATE per subject was 128 (range: 1 to 598).[3]

The summary of adverse reactions with a frequency ≥5% (defined as adverse events occurring within 24 hours of infusion or any adverse event causally related occurring within the trial period) is shown in Table 3.

No subject was withdrawn from a clinical trial due to an adverse reaction. There were no deaths in any of the clinical trials.

Table 3
Summary of Adverse Reactions[a] with a Frequency ≥5% (N = 234 Treated Subjects[b])

MedDRA[c] System Organ Class	MedDRA Preferred Term	Number of ADRs	Number of Subjects	Percent of Subjects
General disorders and administration site conditions	Pyrexia	78	50	21
Nervous system disorders	Headache	104	49	21
Respiratory, thoracic, and mediastinal disorders	Cough	75	44	19
Infections and infestations	Nasopharyngitis	61	40	17
Gastrointestinal disorders	Vomiting	35	27	12
Musculoskeletal and connective tissue disorders	Arthralgia	44	27	12
Injury, poisoning, and procedural complications	Limb injury	55	24	10
Infections and infestations	Upper respiratory tract infection	24	20	9
Respiratory, thoracic, and mediastinal disorders	Pharyngolaryngeal pain	23	20	9
Respiratory, thoracic, and mediastinal disorders	Nasal congestion	24	19	8
Gastrointestinal disorders	Diarrhea	24	18	8
Gastrointestinal disorders	Nausea	21	17	8
General disorders and administration site conditions	Pain	19	17	8
Skin and subcutaneous tissue disorders	Rash	16	13	6
Infections and infestations	Ear infection	16	12	5
Injury, poisoning, and procedural complications	Procedural pain	16	12	5
Respiratory, thoracic, and mediastinal disorders	Rhinorrhea	15	12	5

[a] Adverse reactions are defined as all adverse events that occurred (a) within 24 hours after being infused with investigational product, or (b) all adverse events assessed related or possibly related to investigational product, or (c) adverse events for which the investigator's or sponsor's opinion of causality was missing or indeterminate.

[b] The ADVATE clinical program included 234 treated subjects from 5 completed studies in PTPs and 1 ongoing trial in PUPs as of 27 March 2006.

[c] MedDRA version 8.1 was used.

Immunogenicity

The development of factor VIII inhibitors with the use of ADVATE was evaluated in clinical trials with pediatric PTPs (<6 years of age with >50 factor VIII exposures) and PTPs (>10 years of age with >150 factor VIII exposures). Of 198 subjects who were treated for at least 10 exposure days or on study for a minimum of 120 days, 1 adult developed a low-titer inhibitor (2 BU in the Bethesda assay) after 26 exposure days. Eight weeks later, the inhibitor was no longer detectable, and *in vivo* recovery was normal at 1 and 3 hours after infusion of another marketed recombinant factor VIII concentrate. This single event results in a factor VIII inhibitor frequency in PTPs of 0.51% (95% CI of 0.03 and 2.91% for the risk of any factor VIII inhibitor development).[3,4] No factor VIII inhibitors were detected in the 53 treated pediatric PTPs.

In clinical trials that enrolled previously untreated subjects (defined as having had up to 3 exposures to a factor VIII product at the time of enrollment) , 5 (20%) of 25 subjects who received ADVATE developed inhibitors to factor VIII.[3] Four subjects developed high titer (>5 BU) and one patient developed low-titer inhibitors. Inhibitors were detected at a median of 11 exposure days (range 7 to 13 exposure days) to investigational product.

Immunogenicity also was evaluated by measuring the development of antibodies to heterologous proteins. 182 treated subjects were assessed for anti-Chinese hamster ovary (CHO) cell protein antibodies. Of these subjects, 3 showed an upward trend in antibody titer over time and 4 showed repeated but transient elevations of antibodies. 182 treated subjects were assessed for mulgG protein antibodies. Of these, 10 showed an upward trend in anti-mulgG antibody titer over time and 2 showed repeated but transient elevations of antibodies. Four subjects who demonstrated antibody elevations reported isolated events of urticaria, pruritus, rash, and slightly elevated eosinophil counts. All of these subjects had numerous repeat exposures to the study product without recurrence of the events and a causal relationship between the antibody findings and these clinical events has not been established.

Of the 181 subjects who were treated and assessed for the presence of anti-human von Willebrand Factor (VWF) antibodies, none displayed laboratory evidence indicative of a positive serologic response.

The detection of antibody formation is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to ADVATE with the incidence of antibodies to other products may be misleading.

Post-Marketing Experience

The following adverse reactions have been identified during post-approval use of ADVATE. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Among patients treated with ADVATE, cases of serious allergic/hypersensitivity reactions including anaphylaxis have been reported and factor VIII inhibitor formation (observed predominantly in PUPs). Table 4 represents the most frequently reported post-marketing adverse reactions as MedDRA Preferred Terms.

Table 4
Post-Marketing Experience

Organ System [MedDRA Primary SOC]	Preferred Term
Immune system disorders	Anaphylactic reaction[a] Hypersensitivity[a]
Blood and lymphatic system disorders	Factor VIII inhibition
General disorders and administration site conditions	Injection site reaction Chills Fatigue/Malaise Chest discomfort/pain Less-than-expected therapeutic effect

[a] These reactions have been manifested by dizziness, paresthesias, rash, flushing, face swelling, urticaria, and/or pruritus.

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Living Fit With Von Willebrand Disease

(Continued from page 1)

their symptoms without a diagnosis until a major bleeding event occurs. Lisa describes how a routine tonsillectomy almost cost her life and how she eventually found her way to a diagnosis. Here is Lisa's story:

I was very healthy, active and in great shape when I went in for a routine tonsillectomy during my college years. I never expected this simple procedure to end up a life or death battle. I had the surgery about ten days before Christmas because I had been suffering from a lot of pain in my ears. On Christmas day, I started to bleed. I had my throat cauterized and was sent home. I started to hemorrhage again and this time almost didn't make it to the hospital. I almost bled – out on the way to the emergency room. The ENT specialist ended up working on me all night long to try and save my life. If only I had been diagnosed early on in my life, my bleeding episodes could have been reduced.

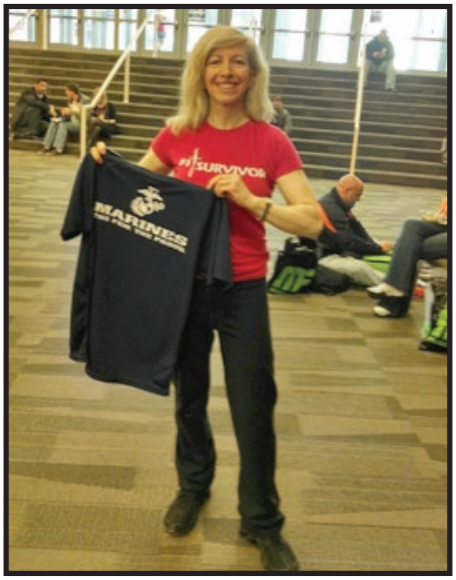
At the time of my surgery, the doctors and specialists didn't know how to really explore why I had so many bleeding episodes. I hemorrhaged about twelve to fifteen times. I would bleed every twelve to twenty-four hours just like clockwork.

Eleven years later, when I had better health insurance, I had more extensive blood tests and was finally diagnosed with VWD type 1. Thankfully now I knew what I was dealing with and learned how to live with it. The hard part was over, now it was how to adapt my life accordingly. I know that I am not the only women who has been diagnosed later in life, there are so many other women out there like my situation.

Despite my bleeding disorder, I have always loved and excelled in sports. During junior high school I competed in archery and was advised to train and try out for the Olympics. Due to lack of finances I never made it to the next level so I looked at sports that didn't cost so much and earned my green belt in Shorin – Ryu karate. During my college years I eventually made it to first degree black belt. I had suffered from internal bleeding after my green belt test after getting kicked really hard in the ribs. I coughed up some blood for about a week after and then was ok. I then became interested and started weight training and bodybuilding with the goal of competing. Many weightlifters encouraged me to compete in powerlifting – but I favored bodybuilding. I trained hard and joined a team of competitors called Body Armor.

I started the hardcore fitness regime of bodybuilding style training and fitness dieting. The results were amazing! I got into even better shape and was able to do four National Physique Committee (NPC) shows. It was hard to believe that I had once survived a life threatening bleeding episode and didn't think I'd ever leave the hospital alive! I was now an NPC level athlete with a long way to go. I won a sword for 4th place which has become part of my business logo.

I'm a firm believer in getting into some



level of fitness and maintaining it depends on your diagnosis, age and ability. My goal is to motivate others with bleeding disorders to get into better shape. It's even more important for those with health challenges to get into shape. It can help you look and feel better. I have written for both fitness and fashion magazines with the idea of using my own background as an example to others who may have the same or similar experiences or issues. I am also a survivor of stage 1 breast cancer in 2008. I continued to maintain my healthy lifestyle and trained throughout radiation treatment. I am here as proof that there is life after illness!

Lisa N. resides in Pennsylvania. She holds a BA in Psychology. She writes a blog on her website: www.fitsurvior.com and has tried out for the American Gladiators television show.

Bowling Marathon to Benefit WPCNHF

The Western Pennsylvania Chapter of the National Hemophilia Foundation Strikes Out Bleeding Disorders

Starting on April 1, 2015 our Bowling for Bleeding Disorders fundraising campaign began. It ended on May 3rd with WPCNHF's 3rd Annual Bowling for Bleeding Disorders bowling marathon.

Bowling for Bleeding Disorders was once again held at Paradise Island Bowl in Neville Township, Pennsylvania. This year, 11 teams bowled for three hours. The cost to bowl was $25 per participant which included shoe rental, bowling, pizza, wings, and unlimited soft drinks.

Trophies were given out during the event to the highest scoring and lowest scoring bowler and team and also to the highest fundraising team. The highest fundraising team award went to Gino's Gutter Gang! Way to go!

Nearly 60 people attended the event. The sponsors of the event included Baxter, The Hemophilia Center of Western Pennsylvania, Bayer, Cottrill's Specialty Pharmacy, Novo Nordisk, Octapharma, and Pfizer. Over $17,000 was raised to benefit the Western Pennsylvania Chapter of the National Hemophilia Foundation.

WPCNHF would like to thank all who attended and participated in making the 3rd Annual Bowling for Bleeding Disorders the most successful one yet!

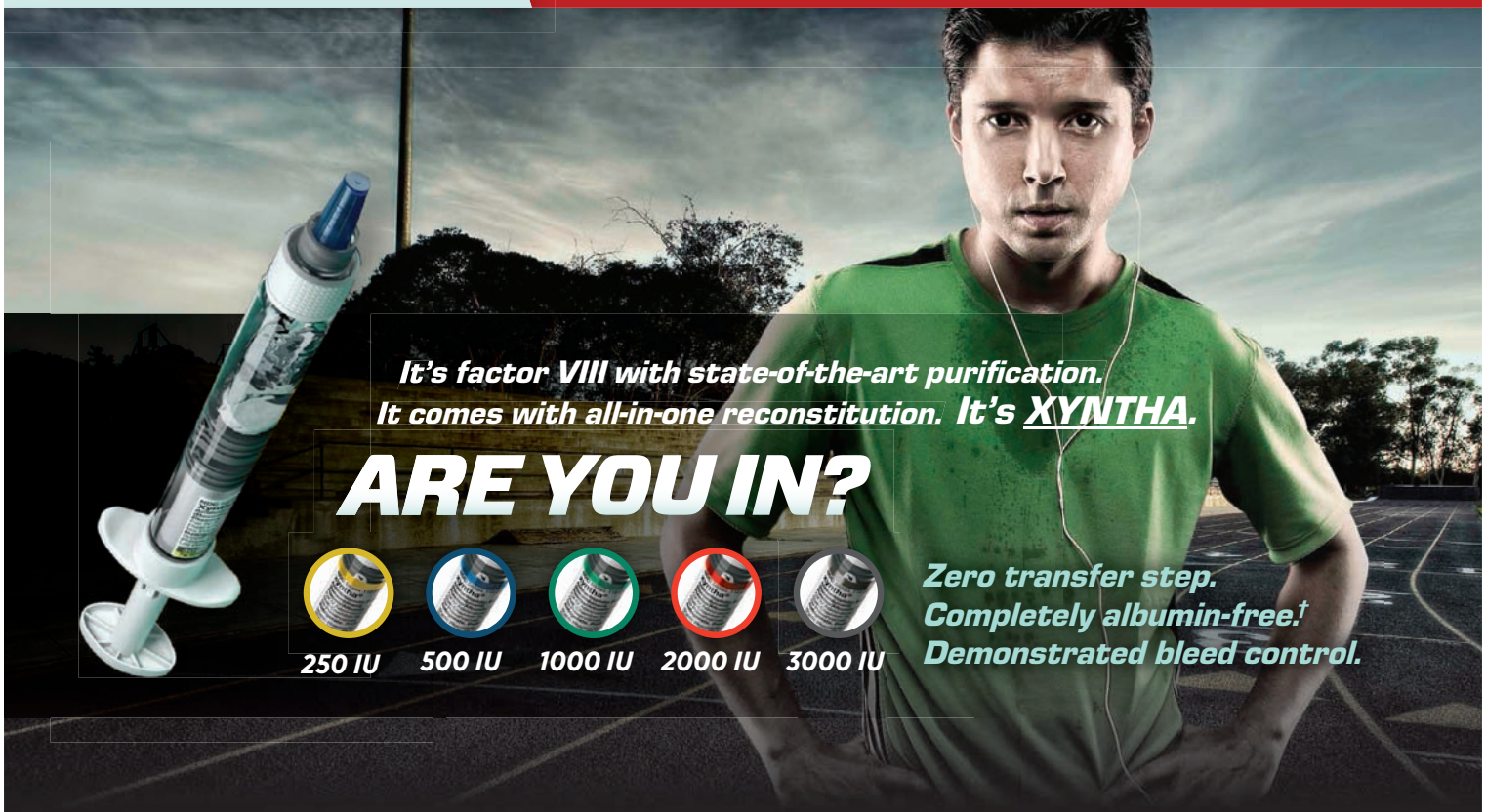
xyntha® solofuse®

Antihemophilic Factor (Recombinant)

FREE TRIAL—Get In and Get It

Get a one-time, 1-month supply up to 20,000 IU at no cost to you—talk to your health care provider to see if XYNTHA® SOLOFUSE® is right for you. For first-time use by commercially insured patients only. Terms and conditions apply.*

See FreeTrialXyntha.com—or scan the QR code.



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, 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® 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, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736.

†The chemically defined cell culture medium in which the Chinese hamster ovary (CHO) cells are grown contains recombinant insulin but does not contain any materials derived from human or added animal sources.

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

Save on XYNTHA‡

‡Terms and conditions can be found at XYNTHA.com.

Pfizer RxPathways™

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

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December 2014

Pfizer

xyntha®

Antihemophilic Factor (Recombinant)

xyntha® solofuse®

Antihemophilic Factor (Recombinant)

℞ 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 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-0500-9.0, revised 10/14.

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Harrisburg Day

By Katie Berry

It was Monday morning, and I had to get up early - very early - but not for school. My brothers, father, and I were going to the state capitol, Harrisburg, to talk with people in the government about money for research into bleeding disorders. It was April 20th, and it was early.

We drove to Harrisburg from Erie because we felt it was important to volunteer and help get the message out about bleeding disorder programs and services. Several people in my family have bleeding disorders, and these programs are important to them and to people like us. And my dad said it would be a good lesson in how our government works.

After a short discussion on our message, we were split into groups, given handouts to give to our senators and representatives, and given visit schedules. We then went to meetings in the Capitol with the senators and representatives to talk about funding our programs. My dad and another man on our team, Dr. Miller, did most of the talking, but I felt I was helping just by being there. I could tell it was important that the senators and representatives see the people like me who need their help. The senators and representatives were very nice, listened to our stories and to our requests, and promised their support when the state makes its budget.

I'm glad to have helped. It was a very long day, but I feel we made a difference not just for me, but for others with bleeding disorders, too. Although next time, I'd like to get up later!

Happy Summer from the HCWP

We hope all of you are enjoying the weather. We have had a busy few months between our outreach clinics and camp. Some recent excitement at the Center included a twinning visit with Dr. James Rwehebura from our Tanzanian partner, Muhimbili National Hospital. Our staff had a reciprocal opportunity to discuss, listen, and learn with Dr. Rwehebura regarding treatment, care, and resources. Also at the Center, our genetic counselor, Michelle Alabek will have a student shadowing her for the summer. Her name is Megan Ensinger. She is in her second year of her Masters in Genetic Counseling degree at University of North Carolina – Greensboro. Another wonderful announcement is our new clinic manager, Deborah J. Solvay, MSN, RN, CCRN. Deborah brings over 15 years of management experience to the Center.

As the summer moves along, please remember that in addition to packing for your summer vacation, contact us to request a travel letter, whether you are flying or driving, about two weeks prior to your trip to ensure timing for doctor review and signature. It is also a good time to check your medical ID jewelry. Is it current? Are you wearing it? Wearing medical ID jewelry gives a voice to you/your child when unable to speak in an emergency circumstance. Call the Center if you need to update or get one. An additional summer reminder for the kiddos (and adults, alike), please wear your helmet. The Center has helmets available on site. Please ask when you are in the office so that we can provide your child with one.

The Hemophilia Center of Western Pennsylvania

The Hemophilia Center of Western Pennsylvania clotting factor program was established in 2000 as a complement to the Center's other comprehensive care services. The clotting factor program allows the Center the opportunity to offer clotting factor to its patients, thereby supplementing its comprehensive treatment care model and providing the best possible care for its patients.

Please contact the Center at (412) 209-7280 for more information about how this program can benefit you and the entire bleeding disorder community.

The Hemophilia Center of Western Pennsylvania supports patient choice consistent with the Veterans Health Care Act of 1992 and maintains a freedom of choice policy where patients are informed of their choices regarding factor replacement products.

Factor Program Services
- All factor product brands available
- Online factor ordering available
- 24 – 48 hour delivery
- Same day courier service for emergent needs
- On-call services, 24/7
- Home treatment supplies
- Lot tracking for recall notification
- Online home treatment records
- Insurance benefit information assistance

Patient Benefits
- Direct communication and service from the Center's treatment team
- Support of the Center's operations
- Expansion of patient services

Spotlight on the Member: Johnson-Huber Family

Delores Johnson-Huber, a Certified Nurse Assistant, lives in Clairton, PA, with her two children. Her son Ethan, age 8, and her newborn son, Kyrie, both have severe Hemophilia A. Like many other parents who have multiple children, Delores can already feel the difference between being a first-time parent and one with experience behind her, and she has a great sense of humor about the differences (calling to mind a recent diaper commercial that depicts that very thing)! In addition to parenting experience, having knowledge about hemophilia and experience caring for a child with hemophilia has helped make that aspect of parenting go more smoothly the second time around. In addition, Delores has been diagnosed with von Willebrand disease and was treated with factor following the birth of her second child. She said it has made a huge difference in her recovery from childbirth.

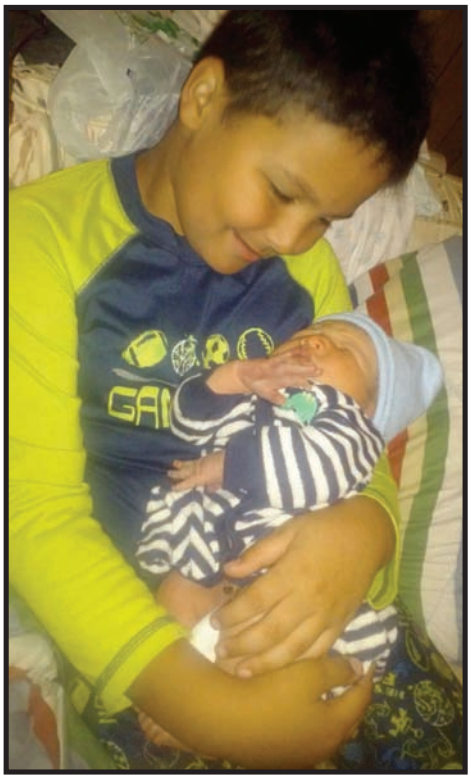
When her first child was born, Delores didn't know he had a bleeding disorder until after he was circumcised and the bleeding wouldn't stop. Ethan was tested and then treated with factor to control the bleed. This time, Delores was tested during pregnancy and found out that her second son had hemophilia before he was born. Kyrie was given factor before the procedure and didn't have any complications.

Ethan's first year was pretty uneventful, as far as bleeds were concerned (with the exception of his circumcision). However, he began to have frequent nose bleeds and needed to be treated accordingly. Due to his frequent infusions, he had a port implanted when he was approximately 18 months old. To control his bleeds, he required factor at least three times a week and sometimes up to twice a day. His port remained in him for several years. Unfortunately, he had numerous port infections and was hospitalized for months at a time, spending the better part of his toddler years in the hospital. The port was removed when he was almost four years old and since then factor has been infused through a vein in his arm.

When Ethan was about 4 ½ years old, he entered a study for a longer-lasting factor and he no longer had frequent nose bleeds. As a result, Ethan was able to be more active and participate in activities most kids his age did. When he was old enough, Ethan went to school. Unfortunately, Delores was called to the school frequently regarding concern over potential bleeds. Last year, she moved to a new school district and the change has been positive for everyone. The school nurse is a former nurse from Children's Hospital and she is quite comfortable assessing bleeds. Ethan adjusted quickly to his new school; he just finished the third grade and is an honor student!

This past year, Ethan played on a baseball team for the first time! He's the catcher for his team and is doing a great job! His coach obtained protective equipment, specifically to help him prevent bleeds or injury. As a bonus, all of the activity has helped him shed about 15 pounds and has him feeling more energetic. Delores also noted that his factor dose was adjusted for the weight loss. She enjoys spending time at the field, watching Ethan play baseball.

Last summer, Ethan attended Camp Hot-to-Clot for the first time. While at camp, he self-infused for the first time and has been self-infusing ever since! He attended Camp Hot-to-Clot again this year and also attended Camp Hemovon for the first time. The family has been active with the Chapter the last few years and has attended a number of educational and social events. Ethan has enjoyed attending a Pittsburgh



Riverhounds soccer game, Pittsburgh Pirates Baseball game, and the Winterfest at Dave & Busters. He looks forward to seeing friends he made at camp and other programs at these events. Delores and Ethan also attended the NHF Annual Meeting in Washington, D.C. with the Chapter last fall.

Delores and Ethan are more than willing to share their stories and experiences with others in the community. In fact, when Ethan was only four years old, he was asked to talk with some children with ports who were his age or younger about having his port removed and receiving his treatments through a vein in his arm instead. A tip that Delores likes to share with other families who are beginning home infusion is to make a special song playlist or have a special video that your child is only allowed to play during the infusion process. She found that these things helped her child to relax and stay still during infusions.

Food & Fitness Basics

(Continued from page 1)

Directions:
In a small mixing bowl, combine shallots, garlic, honey, and ¼ cup Aprihop together

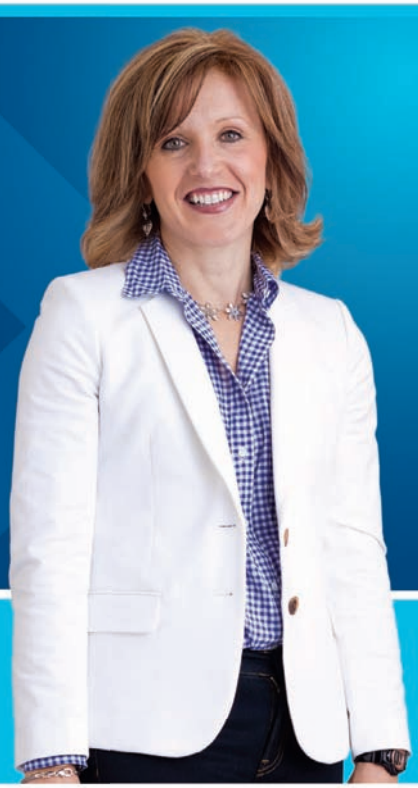
1. In a small sauce pan, combine sugar, ½ cup of sliced apricots, and 1 cup Aprihop beer to a medium simmer, allow this to reduce down to about half-way. The consistency should be thicker, yet still loose like a jelly.
2. Add the apricot mixture to the mixing bowl and combine.
3. Whisk in the oil to create an emulsification.
4. Adjust the seasoning with salt.
5. Toss with arugula enough just to coat.
6. Garnish salad with goat cheese, thin slices of dried apricots and slivered almonds. Scoop into endive leaves if desired.

Tips:
Honey helps keep foods from getting bitter, when cooking with beer. Arugula is a peppery flavored lettuce that goes well with sweet dressings.

ELOCTATE®
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

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 Christine Rowe
E: christine.rowe@biogen.com T: 267-249-8372

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.

Biogen

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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.
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44279-01

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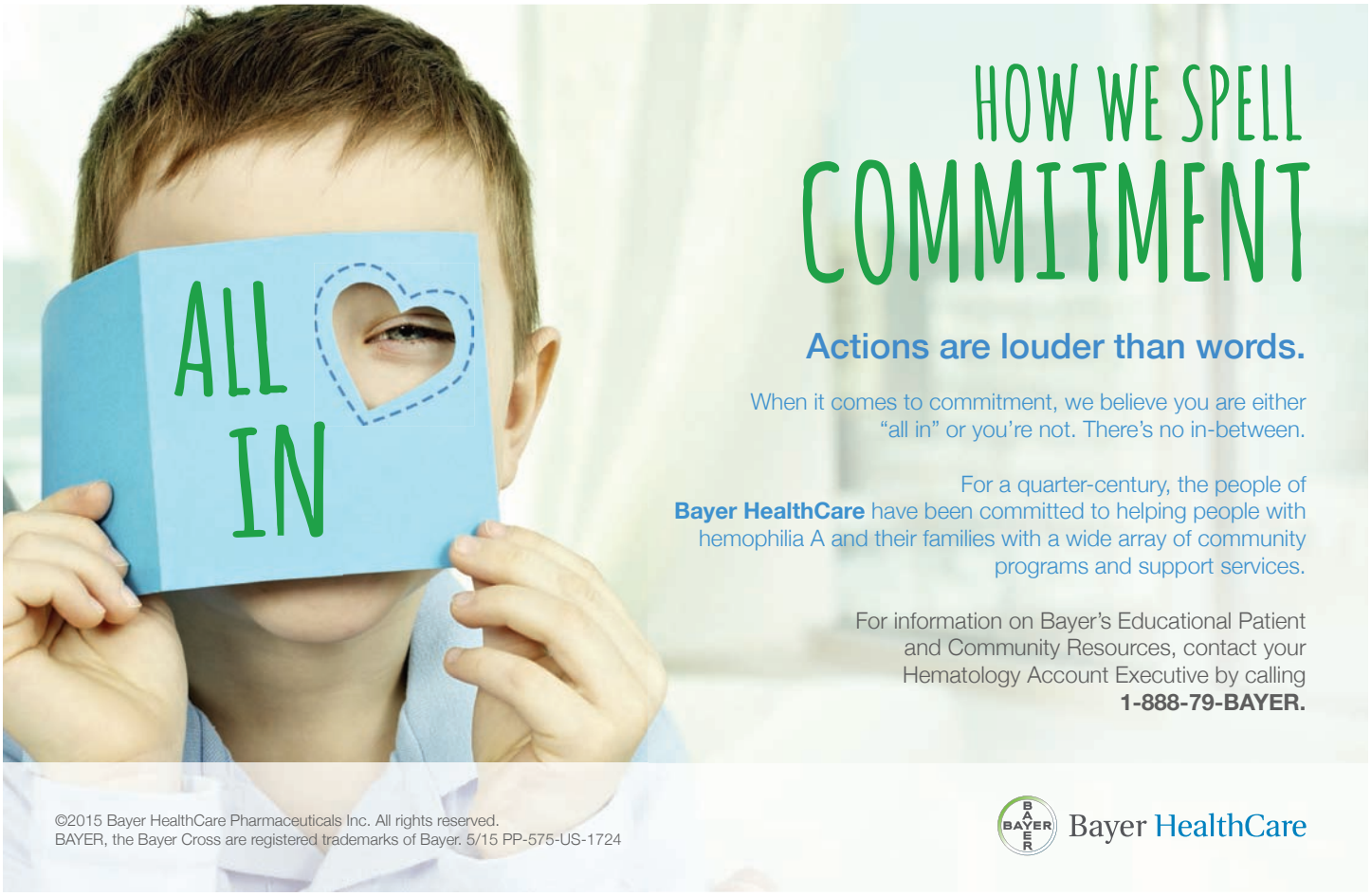
Issued June 2014



HOW WE SPELL
COMMITMENT

Actions are louder than words.

When it comes to commitment, we believe you are either "all in" or you're not. There's no in-between.

For a quarter-century, the people of **Bayer HealthCare** have been committed to helping people with hemophilia A and their families with a wide array of community programs and support services.

For information on Bayer's Educational Patient and Community Resources, contact your Hematology Account Executive by calling **1-888-79-BAYER.**

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Staff office hours are Monday through Friday from 9 a.m. until 4 p.m. Every attempt will be made to return calls received during regular office hours on the same day.

WPCNHF Wish List

The Chapter is always doing fundraisers to raise money for our educational programs and member support activities but sometimes we just need a few small things for the office. WPCNHF has a list of items needed in the office. If you, or anyone you know, is interested in donating any of the following please contact the office at info@wpcnhf.org or call us at 724-741-6160.

- White copy paper by the ream or by the case
- Colored copy paper by the ream for invitations and newsletter inserts
- Legal pads for note taking
- Sticky Notes
- Forever U.S. Postage stamps
- 10 x 13 Ready-seal envelopes for newsletter mailings
- Paper towels

Our Mission:

WPCHNF strives to enrich the lives of those with bleeding disorders in Western Pennsylvania and respond to the needs of the community in a dynamic environment.

Hemogram is published quarterly by the Western Pennsylvania Chapter of the National Hemophilia Foundation. The contents of this newsletter may be reproduced freely. The material in this newsletter is provided for your general information only. WPCNHF does not give medical advice or engage in the practice of medicine. WPCNHF under no circumstances recommends particular treatments, and always recommends that you consult your physician or treatment center before pursuing any course of treatment.

Camp Hot-to-Clot

Time travel was the theme this year and we sure had a lot of fun with it! Camp Hot-to-Clot, which was held from Sunday, June 7 – Saturday, June 13, at Camp Kon-O-Kwee, in Fombell, PA, started a day early for our Leaders-in-Training (LITs). The LITs (select campers who applied, interviewed, and were chosen for the Leaders-in-Training program) attended training on Saturday and helped get things ready for camp. Sunday morning they constructed a time machine and then attended additional training sessions with camp counselors. At four o' clock, the campers arrived and we were off to a full week of activities!

Each day during breakfast and dinner, someone would enter the time machine and bring back people from other eras. The campers enjoyed some very entertaining skits and also learned about the history of bleeding disorders in the process. Along the way, we met Queen Victoria, Grigori Rasputin, Alexei and his parents Empress Alexandra Feodorovna and Emperor Nicholas II of Russia, a knight from medieval times, cowboys from the wild west, Dr. Erik von Willebrand, Dr. Judith Graham Pool… you never knew who was going to come out of the time machine next!

Throughout the week, campers had the opportunity to participate in the many activities that Camp Kon-o-Kwee has to offer, including boating, fishing, archery, BB range, disc golf, soccer, gaga, volleyball, swimming, dancing, drama, arts & crafts, yoga, deck hockey, basketball, splash pad, climbing wall, low ropes, high ropes, and zip line!

Theme-related activities were also incorporated throughout the week. The campers created individual time capsules to bury/store at home. In addition, one large time capsule for Camp Hot-to-Clot was assembled. What went into the Camp Hot-to-Clot time capsule? You'll have to check back in 10 years, when the campers at Camp Hot-to-Clot 2025 open it! The campers enjoyed participating in a medieval tournament that included sword fighting, castle building, and jousting—Camp Hot-to-Clot style! The week also included a dance party, tie-dying camp T-shirts, and a movie with a time-travel theme.

In keeping with Camp Hot-to-Clot tradition, the campers participated in a service project to help give back. This year, they assembled personal hygiene kits to be distributed by Community Human Services to homeless people in Pittsburgh. And to help educate the public, the teenagers create a couple of "Public Service Announcements" (PSAs): one for school nurses and one for the general public regarding misconceptions about bleeding disorders. A link to the PSA on misconceptions can be found on the Chapter's website.

During the week, there were also opportunities to learn more about bleeding disorders. In addition to the time travel skits, campers learned about self-infusion, treating bleeds, and about different types of bleeding disorders. A couple of brave young campers even self-infused for the first time and earned the Big Stick Award! Other campers, who don't need to infuse, opted to learn the process in order to support their sibling or friend and earned the Stick Together Award!

Biotherapies for Life™ CSL Behring

Heritage

At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

Community

We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

Innovation

As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.

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www.CSLBehring-us.com COA13-08-0045 9/2013

From Baxter's BioScience to Baxalta...

Baxter's BioScience is expected to become Baxalta in mid-2015.

At Baxter's BioScience, we see a world of endless possibilities for our patients. And although our name may be changing to Baxalta, our commitment to you is as strong as ever. At our foundation is an enduring heritage of innovation and advocacy. Your life is our inspiration to make a meaningful difference, so you can dream big, and experience life. We are excited about the future and hope you are too!

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USBS/MG1/15-0020(1) February 2015

Baxter

Western Pennsylvania Chapter of the National Hemophilia Foundation
20411 Route 19, Unit 14
Cranberry Township, PA 16066
Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167
info@westpennhemophilia.org