Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Spring 2017
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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**

Teen Retreat

By Julia Shoemaker

From January 6-8, a group of teenagers from the Western Pennsylvania Chapter of the National Hemophilia Foundation attended a retreat at the Family Resources Retreat Center, in Mars, PA. The retreat was supported by the Hemophilia Center of Western PA. During the weekend, the teens helped the bleeding disorders community and themselves in many ways. They did many different things; some were more fun than others, but they were all very beneficial to everyone.

The first night was mainly getting settled in, meeting new people, and catching up with old friends. Saturday would be an exhilarating day for the teens. The weekend included sled riding and puzzles. The weather was frosty, so

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2017 Iced Tees Winter Golf Outing and Chili Cook-Off

The Second Annual Iced Tees Winter Golf Outing and the First Annual WPCNHF Chili Cook-Off were held at Diamond Run Golf Club in Sewickley on Saturday, February 25. Golfers arrived at Diamond Run at 9am and enjoyed an assortment of delicious donuts donated by Peace Love and Little Donuts of Wexford. Each golfer received a t-shirt and goodie bag filled with a variety of golf and winter weather items.

At 10am the golfers teed off for the 9-hole scramble. Despite being prepared for rain and snow, the rain cleared by the time the golfers teed off and the weather remained in the mid-50s. A tee sign was displayed at each hole containing a fact about Hemophilia or von Willebrand Disease.

The Chili Cook-Off was held immediately following the golf outing. Four contestants competed for their chance to win a trophy and a $100 grand prize. Everyone had a chance to taste and vote on their favorite. It was a close call between Michelle Logreco's Michelle's Chili, Bill Shufesky's Billium's Chili, Adam Boyle's Sweet and

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Teen Retreat

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the sled riding didn't last too long! The staff set up an escape room; and in case you have never heard of one, it is a huge puzzle made up of tons of smaller puzzles. It took both teams about an hour each to solve the puzzles.

One thing that everyone was very proud of was doing was something for National Bleeding Disorders Awareness Month, which is in March. The teens took time to create announcements to send to schools to inform students, teachers, and nurses about bleeding disorders. They did all of the research, wrote the scripts, and even filmed some of the teens making the announcements; of course, with the help with the counselors and staff. By the end of the weekend, the group decided to do more things like this. They are going to be expanding Teen Group activities to include service to local community organizations, as well as the Chapter.

By the end of the weekend, the teens made a lot of new friends, had a lot of fun, and accomplished a lot of work toward helping the chapter and getting the word out about bleeding disorders!

Pool Party

Over 45 people attended the Chapter's first Pool Party! It was great to meet new families and see old friends! Our members and their friends enjoyed the Aquatics Center the Rose E. Schneider Family YMCA, which included a Lap Pool, Warm Water Pool, and a Family Fun Pool with Sprays and a Slide! They also had access to the community game room. After a couple hours of pool time, everyone gathered in the community room for pizza and snacks.

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

For patients with Hemophilia A, the FDA has now approved ADYNOVATE® for
+ Use in children under 12
+ Use in surgery

PROVEN PROPHYLAXIS + SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE =

moments YOUR WAY

*ADYNOVATE allows you to infuse on the same 2 days every week.

The pediatric study (N=73) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months[1,2]

+Sixty-six patients (32 patients aged <6 years and 34 patients aged 6 to <12 years) received 40-60 IU/kg of ADYNOVATE prophylactically, twice weekly[2]

+Children experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds[1,3]

+38% (n=25) of children experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds[1]

Talk to your doctor and visit ADYNOVATE.com

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. 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.

References: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc. **2.** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print]. **3.** Data on file; Shire US Inc.

S26377 01/17

Shire

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient 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.

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 that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. 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® [Antihemophilic Factor (Recombinant)]

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

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.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

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.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

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.

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 health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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.

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Shire

Letter From The Executive Director, Alison Yazer

Dear Chapter Members and Friends,

Hopefully by now the snow is all behind us and nicer weather is here to stay! I hope that our spring newsletter finds you and your family well. It has been a busy few months for the Chapter as we continue to plan programs and fundraisers for the remainder of the year. I hope you take the time to look over the events that occurred earlier this year and plan to participate in some of the events that will take place in the upcoming months.

We work hard to offer a range of events – trying to balance educational with social – that will appeal to a wide variety of people. If there's something you'd like to see us offer – please let us know and we'll see what we can do. We are here to serve you – but we can only do so with your input.

Sincerely,

Alison R Yazer
Executive Director

CAMP HOT-TO-CLOT

SAVE the DATE!!!

August 6-12, 2017

Look for a registration reminder and additional instructions in April!

IMPORTANT DATES

Registration opens: May 1, 2017
Registration closes: June 30, 2017
Medical forms due: July 14, 2017

Camp Hot-to-Clot is sponsored by the Hemophilia Center of Western Pennsylvania for children with bleeding disorders and their siblings, ages 7-17 years old. If you think your child/children are eligible, but you did not receive a Save the Date card for Camp Hot-to-Clot 2017 in the mail, please contact CampH2C@itxm.org or 412-209-7344 to request that your child/children be added to the camp mailing list.

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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
- Sticky Notes
- Forever U.S. Postage stamps
- 10 x 13 Ready-seal envelopes for newsletter mailings
- Paper towels

Mission Statement:

WPCNHF 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.

Calendar of Upcoming Events

Saturday, April 1
Cornhole Tournament
Oakdale, PA

Tuesday, April 18
State Advocacy Day
Harrisburg, PA

Saturday, April 29 – Sunday, April 30
Education Weekend
Seven Springs, PA

Saturday, May 6
New Parent Network
Pittsburgh, PA

Sunday, July 16
New Parent Network
Moraine State Park

Wednesday, July 19
WPCNHF Annual Meeting
Homestead, PA

Sunday, August 6 – Saturday, August 12
Camp Hot-to-Clot
Fombell, PA

Saturday, September 9
Hemophilia Walk
North Park Boathouse
Allison Park, PA

Saturday, September 9
Run For Their Lives 5K
North Park Boathouse
Allison Park, PA

Friday, September 22
New Parent Network
Erie, PA

Saturday, September 23
Infusion Day
Erie, PA

Saturday, October 7
Oktoberfest
Pittsburgh Zoo & PPG Aquarium
Pittsburgh, PA

Sunday, October 29
Booling for Bleeding Disorders
Neville Island, PA

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!

Important facts about Helixate FS and Kogenate FS

- Kogenate FS and Helixate FS contain the same factor (active pharmaceutical ingredient and formulation) and are manufactured by Bayer in the same facility
- Bayer has an agreement to supply this factor to CSL Behring, who markets it as Helixate FS
- Bayer's supply agreement with CSL Behring will continue through December 31, 2017, at which point Helixate FS will no longer be manufactured
- Bayer will continue to manufacture Kogenate FS
- Kogenate FS and Helixate FS have different reconstitution systems

Kogenate FS is covered by all major insurance companies

- CVS/Caremark and United Healthcare recently announced that Helixate FS will no longer be covered under some of their commercial prescription plans as of January 1, 2017
- You can check with your insurance provider for any recent changes to the coverage status of Helixate FS

To learn more, visit ContinueFactor.com.

Talk to your healthcare provider to see if Kogenate FS may be appropriate for you.

IMPORTANT SAFETY INFORMATION (CONT'D)

- Your body can make antibodies, called "inhibitors," against Kogenate FS or Helixate FS, which may stop Kogenate FS or Helixate FS 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.
- Other common side effects of Kogenate FS and Helixate FS are local injection site reactions (pain, swelling, irritation at infusion site) and infections from implanted injection device. Tell your healthcare provider about any side effect that bothers you or does not go away.
- Call your healthcare provider right away if bleeding is not controlled after using Kogenate FS or Helixate FS.

For additional important risk and use information, please see the Brief Summary for these products on the following page.

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

Kogenate FS (kō-jen-ate)
Antihemophilic Factor (Recombinant)
Formulated with Sucrose

Helixate FS (he-liks-āt)
Antihemophilic Factor (Recombinant)
Formulated with Sucrose

Brief Summary of Kogenate FS and Helixate FS Patient Product Information

This leaflet summarizes important information about Kogenate FS and Helixate FS. 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 Kogenate FS and Helixate FS. If you have any questions after reading this, ask your healthcare provider.

Do not attempt to self-infuse unless you have been taught how by your healthcare provider or hemophilia center.

What are Kogenate FS and Helixate FS?

Kogenate FS and Helixate FS are medicines 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.

Kogenate FS and Helixate FS are used to treat and control bleeding in adults and children with hemophilia A. Your healthcare provider may give you Kogenate FS and Helixate FS when you have surgery. Kogenate FS and Helixate FS can reduce the number of bleeding episodes when used regularly (prophylaxis). Kogenate FS and Helixate FS can reduce the risk of joint damage in children.

Kogenate FS and Helixate FS are not used to treat von Willebrand Disease.

Who should not use Kogenate FS and Helixate FS?

You should not use Kogenate FS and Helixate FS if you

- are allergic to rodents (like mice and hamsters).
- are allergic to any ingredients in Kogenate FS or Helixate FS.

Tell your healthcare provider if you are pregnant or breast-feeding because Kogenate FS and Helixate FS may not be right for you.

What should I tell my healthcare provider before I use Kogenate FS and Helixate FS?

Tell your healthcare provider about all of your medical conditions.

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.

Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.

Tell your healthcare provider if you have been told that you have inhibitors to factor VIII (because Kogenate FS and Helixate FS may not work for you).

What are the possible side effects of Kogenate FS and Helixate FS?

You could have an allergic reaction to Kogenate FS and Helixate FS. Call your healthcare provider right away and stop treatment if you get

- rash or hives
- itching
- tightness of the chest or throat
- difficulty breathing
- light-headed, dizziness
- nausea
- decrease in blood pressure

Your body can also make antibodies, called "inhibitors," against Kogenate FS and Helixate FS, which may stop Kogenate FS and Helixate FS 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.

Other common side effects of Kogenate FS and Helixate FS are

- Local injection site reactions (pain, swelling, irritation at infusion site)
- Infections from implanted injection device

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

Finding veins for injections may be difficult in young children. When frequent injections are required your child's healthcare provider may propose to have a device surgically placed under the skin to facilitate access to the bloodstream. These devices may result in infections.

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

How do I store Kogenate FS and Helixate FS?

Do not freeze Kogenate FS and Helixate FS.

Store Kogenate FS and Helixate FS at +2°C to +8°C (36°F to 46°F) for up to 30 months from the date of manufacture. Within this period, Kogenate FS and Helixate FS may be stored for a period of up to 12 months at temperatures up to +25°C or 77°F.

Record the starting date of room temperature storage on the unopened product carton. Once stored at room temperature, do not return the product to the refrigerator. The product then expires after storage at room temperature, or after the expiration date on the product vial, whichever is earlier. Store vials in their original carton and protect them from extreme exposure to light.

Reconstituted product (after mixing dry products with wet diluent) must be used within 3 hours and cannot be stored.

Throw away any unused Kogenate FS and Helixate FS after the expiration date.

Do not use reconstituted Kogenate FS and Helixate FS if it is not clear to slightly cloudy and colorless.

What else should I know about Kogenate FS and Helixate FS and hemophilia A?

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

This leaflet summarizes the most important information about Kogenate FS and Helixate FS. If you would like more information, talk to your healthcare provider. You can ask your healthcare provider or pharmacist for information about Kogenate FS and Helixate FS that was written for healthcare professionals.

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

Further information for Kogenate FS:

Bayer HealthCare LLC
Whippany, NJ 07981 USA
U.S. License No. 8
(License Holder: Bayer Corporation)

For the full prescribing information for Kogenate FS, visit www.kogenatefs.com

Further information for Helixate FS:
Manufactured by:
Bayer HealthCare LLC
Whippany, NJ 07981 USA
U.S. License No. 8 (License Holder: Bayer Corporation)
Distributed by: CSL Behring LLC
Kankakee, IL 60901 USA

For the full prescribing information for Helixate FS, visit www.helixatefs.com

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Washington Days

More than 480 members of the bleeding disorders community attended NHF's Washington Day on March 9. This was a record number of participants in this annual event. People from around the country met with their U.S. Representatives and Senators to talk about bleeding disorders and ask then to support three policies that are critically important to the bleeding disorders community, as they consider changes to the Affordable Care Act:

- Maintain the elimination of lifetime and annual limits on essential health benefits

- Maintain federal requirements for essential health benefits to ensure patient protections are meaningful
- Maintain the Medicaid expansion, including the categorical eligibility for childless men and women and the enhanced federal funding for the expansion population

It's not too late to voice your opinion. Please contact your legislators and let them know why these existing policies are important to you!

Potential Therapy Employs Addition by Subtraction Approach

Recent research suggests that a new understanding of furin, a common protein found in most cells, could have therapeutic implications for people with factor VIII deficiency, or hemophilia A. The new findings, "Circumventing Furin Enhances Factor VIII Biological Activity and Ameliorates Bleeding Phenotypes in Hemophilia Models," were published October 6, 2016, in the journal *JCI (Journal of Clinical Investigation)* Insight. The lead investigator of the study was Valder R. Arruda, MD, PhD, a hematology researcher at The Children's Hospital of Philadelphia. Arruda is also a faculty member of the Perelman School of Medicine at the University of Pennsylvania.

Until now, scientists understood that among its many roles, furin contributes to coagulation. Factor replacement therapies, including factor VIII (FVIII) in hemophilia A and factor IX (FIX) in hemophilia B, contain amino acids that identify and interact with furin as part of the clotting process. However, Arruda and

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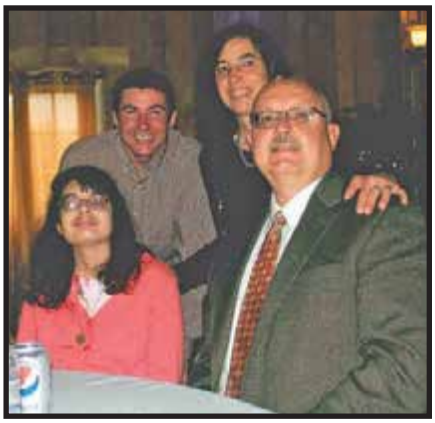
Spotlight on the Member: Meet the Balog Family



Quite often our members say had have never met another person with von Willebrand Disease or Hemophilia until they've attended a Chapter event. That was not the case, however, with the Balog family. Linda Balog first met others living with a bleeding disorder after seeing a notice in a church bulletin about a von Willebrand Disease support group! Although the support group only met a few times, it was enough for Linda to meet others who were living with von Willebrand Disease and from them, learn about the Chapter and about the specialized care they received from Dr. Margaret Ragni and the Hemophilia Center of Western PA (HCWP).

Linda and her husband, Glenn, can appreciate the benefits of receiving care from specialized medical teams. Both of their children (Julie age 23 and Ryan age 19) have von Willebrand Disease (VWD) in addition to other medical conditions. From meeting with specialists and attending various conferences, the Balogs feel their children are receiving the best care possible and benefitting from the latest, most effective treatments. They had learned about the HCWP when Ryan was seven years old and are grateful for the comprehensive care their family has received there, ever since.

The Balogs first learned that Ryan had von Willebrand Disease when he was 18 months old and had pre-op blood work for an adenoidectomy. When his blood did not clot properly, he was referred to the Hematology department and further testing revealed that he had VWD. When the results came back positive, Linda and Glenn decided to have Julie tested and she was diagnosed with VWD, as well.

Julie was five years old when she received her VWD diagnosis. However, she had been dealing with other medical issues since birth. When she was four days old she exhibited signs of a seizure. Upon testing at Children's hospital, it was discovered that she was born with a subdural hematoma. It is not definitive whether the hematoma caused the seizures. The blood was reabsorbed and she didn't require surgery. However, she was left with residual, life-long seizures. It is also not known whether VWD had any impact. Today, due to her seizures, Julie requires supervision and attends a day program. She enjoys volunteering, cooking, dancing, and doing math! Julie treats prophylactically prior to surgical procedures and can typically use Stimate to control most bleeds.

Ryan has had more frequent bleeding episodes than his sister, including many nosebleeds. Due to another medical condition, Ichthyosis, Ryan's skin can be very dry and more susceptible to bleeds. The condition also prevents his skin from sweating. For those reasons, he avoids heavy contact sports. These conditions haven't prevented Ryan from being active, though. Throughout high school he played on the tennis team and had played baseball in previous years. Ryan uses factor to control major bleeds and treats other bleeds with Stimate. He is a student at LaRoche college and is studying to become a math teacher. In addition to college, he works part time. Ryan is also steadily involved in volunteer work. His service includes volunteering at the annual Ichthyosis conference, volunteering monthly for bingo at Cumberland Crossing, and volunteering at Chapter events whenever possible!

The family enjoys traveling. Each year they travel out west and visit different destinations. Last year's trip included a visit to the Grand Canyon. When they are home, in Ross Township, they enjoy walking their Black Lab; going out to eat; and enjoy swimming in the summertime.

The Balogs continue to seek educational opportunities and stay on top of the latest medical information. They look forward to the Chapter's education weekend; not only for the educational programs, but also for the opportunity to interact with other families with bleeding disorders. Linda values the friendships she has made with other members and the lessons she has learned from their experiences. On occasion, she has run into Chapter members in other settings. For example, a few years ago she took her daughter to the hospital to receive radiation treatments for her seizures. Linda remarked that she was surprised and comforted when she saw someone she knew working at the hospital—a friend she had made through attending Chapter events!

Chapter Family Speaks at Town Hall Meeting

Delores Johnson and her two children, Ethan (age 10) and Kyrie (22 months), attended U.S. Representative Mike Doyle's town hall meeting on Saturday, March 18. The meeting was held at Soldiers & Sailors Memorial Hall and Museum; the topic was health care; and approximately 1200 people were in attendance. Both of Delores' children have hemophilia. She and Ethan talked about why the affordable care act is important to them and others in the community. She encourages everyone in the bleeding disorders community to contact their U.S. Representative and Senators and let them know why health care coverage and eliminations of pre-existing conditions is important to them.

If you would like to advocate on behalf of the bleeding disorders community, please contact the Chapter for more information.

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Red Tie Challenge

More than three million Americans have a bleeding disorder—such as hemophilia, von Willebrand disease or rare factor deficiencies—which: prevents their blood from clotting normally; can result in extended bleeding after injury, surgery or trauma; and can be fatal if not treated effectively. In March the Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF) and the National Hemophilia Foundation (NHF) launched the 2017 Red Tie Challenge, which challenges individuals to support WPCNHF and NHF in the fight against bleeding disorders by making a donation and getting creative in wearing a red tie. The "red tie" was introduced as the official symbol of the bleeding disorders community in 2016.

For over 50 years, WPCNHF has been leading the fight against bleeding disorders in Western Pennsylvania and, in partnership with NHF—the largest nongovernment funder of research awards, fellowships and grants—we have advanced the standard of care and the quality of life for our community. To ensure our research, education and advocacy initiatives continue to have maximum impact, we have focused the 2017 Red Tie Challenge on fundraising and, this year, challenge-takers have the option of donating directly to WPCNHF.

Taking the Red Tie Challenge is as easy as 1-2-3:

1. Make a donation to WPCNHF at RedTieChallenge.org.
2. Get a red tie, then record and share your best red tie style with #RedTieChallenge.
3. Challenge your friends to join you in the fight against bleeding disorders.

An enhanced microsite—**RedTieChallenge.org**—serves as the Red Tie Challenge movement's official home on the web. It features a public service announcement, a donation portal, a #RedTieChallenge tracker, an infographic, and downloadable materials for use by students and schools in Western Pennsylvania to bring the Red Tie Challenge into the classroom and raise funds for WPCNHF's initiatives.

WPCNHF wishes to thank the bleeding disorders community and the following companies and organizations for making the Red Tie Challenge possible: Shire, Pfizer, Bayer, Novo Nordisk, CSL Behring, Genentech and The Hemophilia Alliance.

Hemophilia Awareness Bracelets

Coblentz Clotterz are selling handmade Hemophilia Awareness Bracelets to raise money for the 2017 Hemophilia Walk! The bracelets are $5 apiece and all proceeds will go to the Western Pennsylvania Chapter of the National Hemophilia Foundation. If you are interested in purchasing a bracelet or would like to help sell them, please contact Denisa and Gavin at Coblentzcreations@yahoo.com.

Ties That Bond: Nurturing the Needs of Unaffected Siblings

By Amy Lynn Smith | 10.27.2016

Cristina de la Riva (pictured above, with brother Jorge) credits her brother's hemophilia with making their family closer.

Cristina de la Riva, 23, has always been close to her younger brother, Jorge. In fact, she says they are best friends.

Jorge was diagnosed with severe hemophilia A at birth. His hemophilia immediately became a family affair. "When Jorge was diagnosed, our family was diagnosed," Cristina says. "We became a team that was going to figure this out together."

Although she was only 2 years old when Jorge was born, Cristina's parents told her the truth as soon as she was able to understand it. The family got involved right away with the Lone Star Chapter of the National Hemophilia Foundation (NHF) in Houston.

"When I was little, all I remember of hemophilia was my brother crying because he had a shot, so I related to hemophilia very negatively," Cristina says. "But later, as my mom became the director of the Lone Star Chapter, then I associated hemophilia with the community, going to bowl-a-thons, going to walks and doing fun stuff."

"Jorge only lets a few people experience his hemophilia with him, so I think it's made us closer," she says. "That's kind of a gift to the siblings in our community, something that is shared and can be a bonding experience within the family."

Open communication

For Cristina, being the unaffected sibling of someone with a bleeding disorder has been a positive experience overall. In fact, she appreciates the opportunities it has created, such as the chance to advocate and participate in NHF's National Youth Leadership Institute (NYLI), a three-year leadership training program for young adults ages 18 to 24.

But this is not always the case, according to Jeanne Safer, PhD, a psychotherapist and author of The Normal One (Delta, 2003). The title, she says, came from the unaffected siblings in families of children with disabilities or other challenges who self-identify as "the normal one" in the family.

According to Safer, it's important to let unaffected siblings talk about their frustrations and fears. "You can't make somebody feel certain things. You have to allow them to feel what they feel," she says. Parents should avoid telling unaffected siblings to "count your blessings" if they express negativity about their sibling's condition. "That squelches normal responses," says Safer.

Family members should avoid referring to the sibling with a bleeding disorder as having "special needs." After all, Safer says, all children have special needs of some sort. Consistently treating the sibling with a bleeding disorder as special can make unaffected siblings feel that they're not special or that their needs don't count.

Education, observation

Hiding the facts about bleeding disorders from unaffected siblings will only breed fear and uncertainty.

Cristina's parents let her be present for Jorge's clotting factor infusions, so she could see exactly what was involved. "I was in on it," she says. "Otherwise, it would have been this private thing between my father or mother and my brother. I would have felt left out. I would have seen hemophilia as an experience that was separate and foreign to my own."

What's more, Cristina's parents were candid with her about her risk of being a carrier of hemophilia, especially because her mother is a symptomatic carrier. Cristina was tested at age 19 and is not a carrier.

Let them shine

Safer points out that not all siblings will be naturally close. In fact, some aren't comfortable being part of their brother's or sister's care. She urges parents not to force camaraderie in these relationships. She also suggests spending some one-on-one time with unaffected siblings.

"Let them be the center of attention regularly," Safer says. "And let them have their own friends, activities and moments to shine."

"Your family bleeding disorder doesn't have to be something negative in your life. In our family, we became closer because of our bleeding disorder," says Cristina.

Men's Group Update

By Matt Pace

The Men's Group got together at Dave and Buster's in Pittsburgh to watch the Penguins game in February. Although the Pens had some trouble dealing with the Red Wings and the "ghost" in the sky box room at Dave and Busters kept spilling root beer on the table, we had a great time. It was a great chance for us to get to know each other a bit better and share stories about being part of the bleeding disorder community. Be on the lookout for information on future Men's group events. If you have any ideas for an activity you would enjoy, please reach out to Matt (mpace@setonhill.edu) or Janet (janet@wpcnhf.org)!

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN

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

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

Stay empowered by the possibilities.

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

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For the Treatment of Adults and Children with Hemophilia A

NUWIQ®

Antihemophilic Factor (Recombinant)

Because you are unique.

The First and Only Recombinant FVIII Produced in Human Cells Without Chemical Modification or Protein Fusion[1-4]

For more information, contact your **Octapharma Representative:**

KAREN BOWE

PHONE | 717-395-5887

EMAIL | Karen.Bowe@octapharma.com

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.

References: 1. Sandberg H, et al. Thromb Res 2012; 130:808-817. **2.** Casademunt E, et al.. Eur J Haematol 2012; 89:165-176. **3.** Kannicht C, et al. Thromb Res 2013; 131:78-88. **4.** Valentino LA, et al. Haemophilia 2014; 20:1-9.

Date of preparation: 7/2016. NUW-016-CADr

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For the safe and optimal use of human proteins

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

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
- Routine prophylaxis to reduce the frequency of bleeding episodes

NUWIQ is not indicated for the treatment of von Willebrand Disease.

DOSAGE 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 (%) (IU/dL) x 0.5 (IU/kg per IU/dL)
- Dosing for routine prophylaxis:

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

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

DOSAGE FORMS AND STRENGTHS

NUWIQ is available as a white 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 stop the injection 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.

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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:
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Potential Therapy Employs Addition by Subtraction Approach

(Continued from page 9)

his team have discovered that while the furin/FIX interaction is a key "clotting-contributor," furin may not be necessary for a healthy clot to form in people with hemophilia A. They made this discovery by first bioengineering a new variant FVIII protein designed so that it would not interact with furin. They then used that variant in gene therapy experiments in mice with severe hemophilia A, which triggered increased FVIII levels and improved clotting activity in the animals.

Collaborating on the study were investigators from the University of North Carolina (UNC) at Chapel Hill led by Timothy C. Nichols, MD. The UNC team used the same gene therapy on dogs with hemophilia A. They also observed decrease bleeding as a result. In addition, no unwanted immune response occurred from the therapy.

By omitting the furin component, researchers have found a novel way to streamline delivery of the genetic material. "In gene therapy, size matters," said Arruda. "It's important to reduce the gene package for FVIII to the smallest effective size." Deleting the furin-recognition portion both decreases the size of the gene therapy "payload" and enhances its benefits for treating hemophilia A, he added.

Further research is needed before clinical trials in people can be conducted, but the researchers are optimistic about furin's future. "Because this variant provides more efficient bleeding control than currently available replacement drugs, while avoiding immune reactions, this could address the unmet needs of hemophilia A patients worldwide," added Arruda. "It may also advance gene therapy for this disorder as well."

Source: Science Daily, October 17, 2016

SAVE THE DATE

The Hemophilia Center of Western Pennsylvania is proud to host…

Caring for Carriers

This free, 3-part series is designed to support the unique educational and psychosocial needs of carriers and potential carriers of hemophilia. Adult females (age 18 or over) who are carriers of hemophilia or who have a family history of hemophilia are welcome to attend any or all of the events in this series.

Registration is now open for the first event in the series.
To register for this event, contact Michelle Alabek (412-209-7292) or Kathaleen Schnur (412-209-7267).

Improving Communication with Providers
Wednesday evening, April 19, 2017

Description: This session will explore some of the perceived barriers of non-HCWP providers (i.e. PCPs, OB/GYNs) caring for hemophilia carriers. Attendees will be asked to provide input and feedback into development of a tool designed to help carriers and potential carriers facilitate better communication with their providers. A light meal will be served. Registration deadline: April 12, 2017.
Location: Hemophilia Center of Western Pennsylvania
Time and location will be provided upon registration.

Ask the Doctor
June 2017

Description: During this session, attendees will have the opportunity to ask questions about their own care, management, and symptoms. Dr. Margaret Ragni, medical director of HCWP, will guide discussion, provide answers, and offer insights on the current knowledge surrounding management for carriers.
Location and time will be announced at a later date.

Supporting Other At-risk Relatives
September 2017

Description: This final session will focus on the powerful role that women can play in educating and supporting their at-risk relatives, including daughters, sisters, mothers, and more distant relatives. Time will also be provided for informal socializing.
Location and time will be announced at a later date.

HCWP will be mailing out invitations for each event in the series. If you would like to be on this mailing list, contact Michelle Alabek (412-209-7292) or Kathaleen Schnur (412-209-7267) at HCWP.

Space may be limited at some of the events. Preference will be given on a first-come, first-serve basis. No-showing to a session may preclude you from attending future sessions in this series.

IDELVION®
Coagulation Factor IX (Recombinant), Albumin Fusion Protein

He's free to infuse only once every 14 days. **Are you?**

The only FDA-approved treatment for hemophilia B with up to 14-day dosing.* **Visit us at IDELVION.com.**

14-DAY DOSING WITH HIGH LEVEL PROTECTION*

Dosing schedule that fits into your lifestyle

21% FIX LEVELS WITH PROPHYLACTIC USE†

High and sustained Factor IX levels at steady state[1,†]

ZERO BLEEDS MEDIAN AsBR

Zero median annualized spontaneous bleeding rate (AsBR) when dosed at 7 or 14 days in clinical trials

Protection with peace of mind—**low incidence of side effects**

*Appropriate people 12 years and older may be eligible for 14-day dosing. Talk with your doctor.
†Average FIX levels with 7-day dosing over 92 weeks in clinical trials.

Important Safety Information

IDELVION is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

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 prescribing information for IDELVION on next page.

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use IDELVION safely and effectively. Please see full prescribing information for IDELVION, which has a section with information directed specifically to patients.

What is IDELVION?

IDELVION is an injectable medicine used to replace clotting Factor IX that is absent or insufficient in people with hemophilia B. Hemophilia B, also called congenital Factor IX deficiency or Christmas disease, is an inherited bleeding disorder that prevents blood from clotting normally.

IDELVION is used to control and prevent bleeding episodes. Your healthcare provider may give you IDELVION when you have surgery. IDELVION can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use IDELVION?

You should not use IDELVION if you have had life-threatening hypersensitivity reactions to IDELVION or are allergic to:

- hamster proteins
- any ingredients in IDELVION

Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using IDELVION.

What should I tell my healthcare provider before using IDELVION?

Discuss the following with your healthcare provider:

- Your general health, including any medical condition you have or have had, including pregnancy, and any medical problems you may be having
- Any medicines you are taking, both prescription and non-prescription, and including any vitamins, supplements, or herbal remedies
- Allergies you might have, including allergies to hamster proteins
- Known inhibitors to Factor IX that you've experienced or been told you have (because IDELVION might not work for you)

What must I know about administering IDELVION?

- IDELVION is administered intravenously, directly into the bloodstream.
- IDELVION can be self-administered or administered by a caregiver with training and approval from your healthcare provider or hemophilia treatment center. **(For directions on reconstituting and administering IDELVION, see the Instructions for Use in the FDA-Approved Patient Labeling section of the full prescribing information.)**
- Your healthcare provider will tell you how much IDELVION to use based on your weight, the severity of your hemophilia B, your age, and other factors. Call your healthcare provider right away if your bleeding does not stop after taking IDELVION.
- Blood tests may be needed after you start IDELVION to ensure that your blood level of Factor IX is high enough to properly clot your blood.

What are the possible side effects of IDELVION?

Allergic reactions can occur with IDELVION. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

IDELVION might increase the risk of abnormal blood clots forming in your body, especially if you have risk factors for such clots. Call your healthcare provider if you experience chest pain, difficulty breathing, or leg tenderness or swelling while being treated with IDELVION.

A common side effect of IDELVION is headache. This is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full prescribing information, including FDA-approved patient labeling.

Based on November 2016 PI revision.

References: 1. Data on file. Available from CSL Behring as DOF IDL-002.

IDELVION®
Coagulation Factor IX (Recombinant), Albumin Fusion Protein

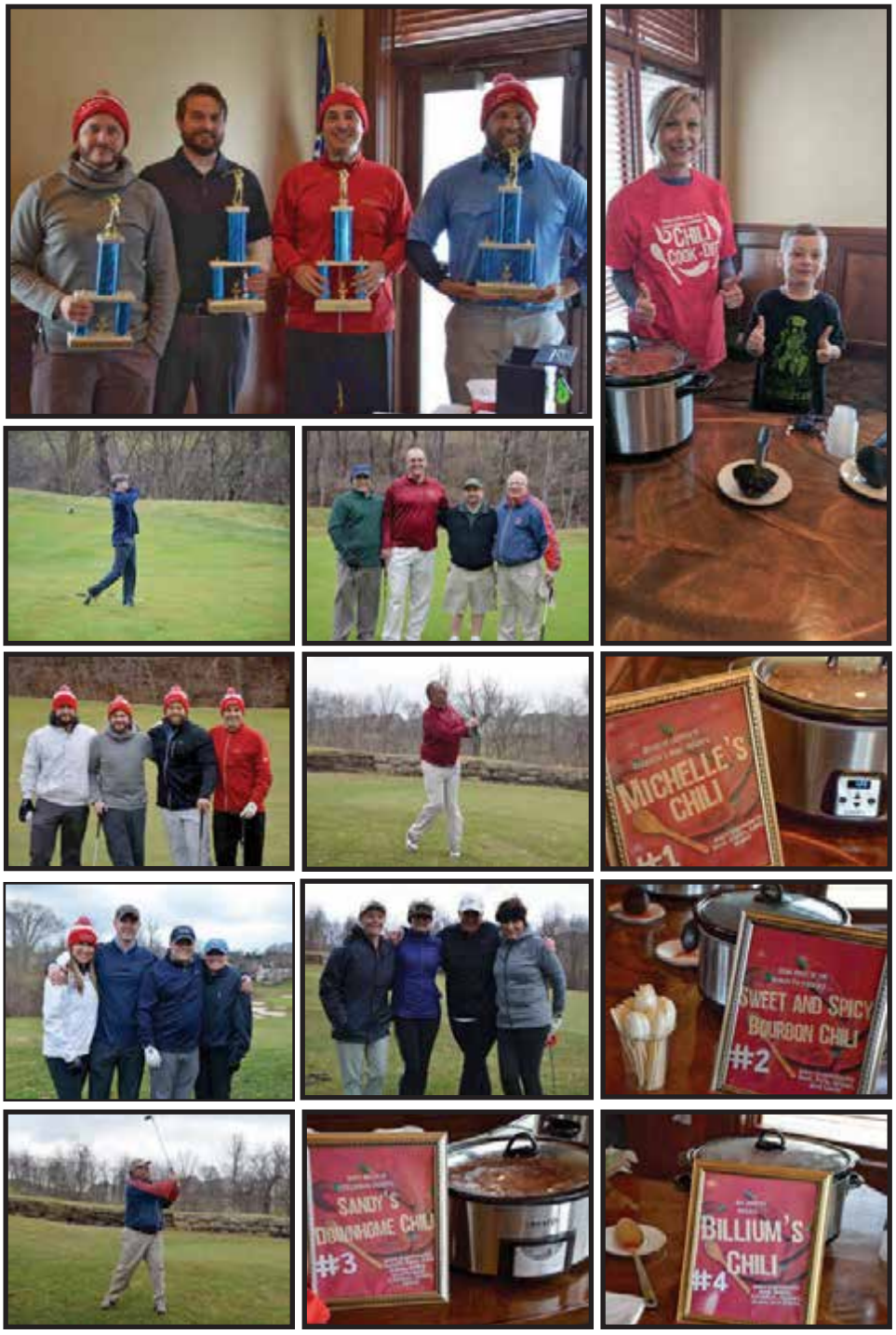
2017 Iced Tees Winter Golf Outing and Chili Cook-Off

(Continued from cover page)

Spicy Bourbon Chili, and Scott Miller's Sandy's Downhome Chili. Scott Miller came out ahead to become the 2017 WPCNHF Chili Cook-Off Champion and donated his prize money back to the Chapter. Thanks, Scott!

Kiss 96.1's DJ, Tall Cathy, joined us to present the awards to the winners of the golf outing. Longest Drive went to Shelly Lyons and Pat Bair. Closest to the Pin went to Bill Shufesky, Matt Pace, and Pat Bair. Third place went to Melissa Dillon, Nancy Rocco, Cindy Yingling, and Gretchen Moran. Second place went to Scott Miller, Anthony Pirrello, John Onorato, and Bill Shufesky. First place went to Nathan Rost, Marcus Morelli, Neil Giles, and Pat Bair.

WPCNHF would like to thank everyone who participated, sponsored the event, donated items, or volunteered their time to help make the event a success! We are excited to report that over $21,000 was raised! 100% of this money will stay local to support the members of the Western PA Chapter of the National Hemophilia Foundation. Please be sure to save the date for the Third Annual Iced Tees Golf Outing which will be held at Diamond Run Golf Club on Saturday, February 17, 2018! We hope to see you there!

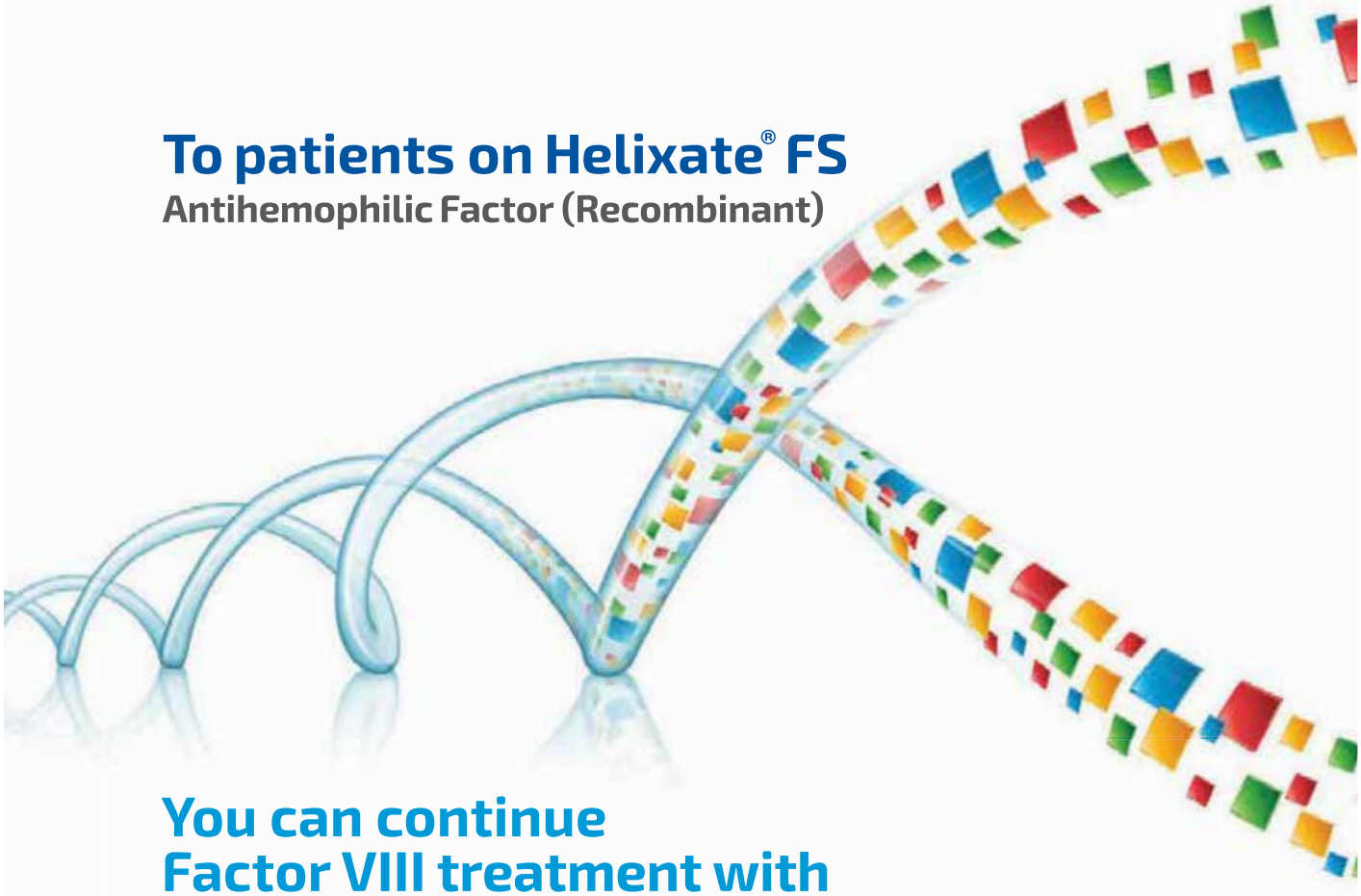


Outreach Programs

The Chapter is continuing its outreach efforts to bring programming to communities in less populated areas of our region. In January, two dinner programs were held in Punxsutawney, specifically for the Amish community. The program Exploring Emotional Well-being in the Hemophilia Community was presented by Nayan Heath, RN. The program gave an overview of mental health disorders, including depression and anxiety, for the general population and for those impacted by a bleeding disorder. We had a very nice turnout on both evenings. We thank Pfizer for sponsoring these informative programs.

If you would like the Chapter to bring a program to a location near you, please send an e-mail to janet@wpcnhf.org or call the office at 724-741-6160. We would love to hear from you!

To patients on Helixate® FS
Antihemophilic Factor (Recombinant)



You can continue Factor VIII treatment with Kogenate® FS Antihemophilic Factor (Recombinant)

INDICATIONS

- Kogenate® FS Antihemophilic Factor (Recombinant) and Helixate® FS Antihemophilic Factor (Recombinant) are medicines used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- Kogenate FS and Helixate FS are used to treat and control bleeding in adults and children with hemophilia A. Your healthcare provider may give you Kogenate FS or Helixate FS when you have surgery. Kogenate FS and Helixate FS can reduce the number of bleeding episodes in adults and children when used regularly (prophylaxis). Kogenate FS and Helixate FS can reduce the risk of joint damage in children without pre-existing joint damage when used regularly.
- Kogenate FS and Helixate FS are not used to treat von Willebrand disease.

IMPORTANT SAFETY INFORMATION

- You should not use Kogenate FS or Helixate FS if you are allergic to rodents (like mice and hamsters) or are allergic to any ingredients in Kogenate FS or Helixate FS.
- Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.
- You could have an allergic reaction to Kogenate FS or Helixate FS. Call your healthcare provider right away and stop treatment if you get rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headed, dizziness, nausea or a decrease in blood pressure.

Western Pennsylvania Chapter of the National Hemophilia Foundation
20411 Route 19, Unit 14
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