Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Summer 2016
Inside this issue

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**

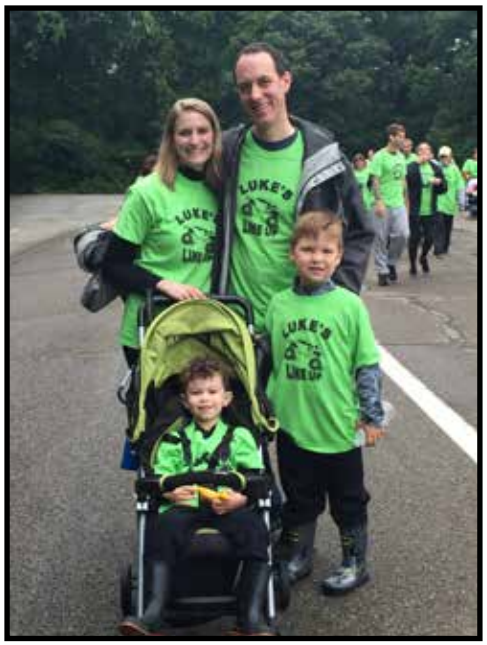
EDUCATION DAY 2016

Thanks to Judith Kadosh, RN, Lead Research Nurse, at the Hemophilia Center of Western PA, the Chapter was able to offer our members one of the most requested program topics, Research and Clinical Trials, at our 2016 Education Day, held on April 16th! Judith covered what's new and exciting in research and the benefits to the bleeding disorders community. Two panelists, Michael Niesslein, an adult who participated in a clinical trial and Martha Songer, a parent of child who participated in a clinical trial, joined Judith and participated in the discussion and answered questions. Participants valued the input from the panelists and the detailed information from Judith. One member commented that he had a clearer understanding on how important participation in clinical trials and keeping accurate infusion logs are to the advancements in care and treatment options for people with bleeding disorders.

In another room at the Regional Learning Alliance, where Education Day was held,

(Continued on page 15)

SPOTLIGHT ON THE MEMBER: MILLER FAMILY



My name is Jen Miller. My husband, Scott, and I are the proud parents of Sam (age 6) and Luke (age 3). Our boys are very active and keep us on our toes. Sam loves sports and is an avid baseball player and swimmer. Luke's interests include swimming, monster trucks and dinosaurs. We enjoy going to Pirates games, having pizza/movie nights, and visiting amusement parks and museums as a family.

When our youngest son, Luke, was born, he surprised us by arriving three weeks early. We didn't know he was saving his biggest surprise until he was 6 months old. At birth, Luke showed no signs that he had a bleeding

(Continued on page 15)

National Hemophilia Foundation Presents

HEMOPHILIA walk℠

Every step makes a difference

SAVE THE DATE

Saturday, September 17, 2016

Registration Check-In Time: 9:00am
Walk Start Time: 10:00am
Distance: 5K (3.1 miles)
Location: North Park Boat House
10301 Pearce Mill Rd
Allison Park, PA 15101
Walk Chair: Kelly Baker

Join us to support the Hemophilia Walk! We will walk to raise critical FUNDS and AWARENESS for the bleeding disorders community. Your support is greatly appreciated!

For more information, please visit www.hemophilia.org/walk or contact: Kara Dornish, Local Walk Event Manager, at 724-741-6160 or kara@wpcnhf.org.

www.hemophilia.org/walk

Participate. Volunteer. Donate.

Run For Their Lives

5K Run

To Register or Donate visit,
http://www.wpcnhf.org
or e-mail
kara@wpcnhf.org

Benefitting the Western Pennsylvania Chapter of the National Hemophilia Foundation

September 17, 2016
Check in begins at 7:30 am
Race begins at 8:30 am

North Park Boat House
10301 Pearce Mill Rd
Allison Park, PA 15101

Letter From The President, Nathan Rost

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.

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 & Walk Kickoff on August 4th 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 the Run for Their Lives®, both on September 17, 2016. This year, we're adding a cornhole tournament to continue to build awareness of bleeding disorders. These events continue to be among our most important fundraisers – allowing 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,

Nathan Rost
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 diversifying locations of our educational programs to enable ALL our members can attend them and I hope you plan to join us for some of these great upcoming events.

We are fresh off our first ever Family Camp weekend and I can tell you it was a blast! Keep an eye out for future articles about it as well as Facebook and Instagram posts from the weekend. This weekend was different from our usual, every other year education weekend, and while it was a very different kind of event, I believe that people enjoyed themselves and got a great deal out of it.

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

Board of Directors

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Nathan Rost

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Executive Director
Alison Yazer

Member Services Manager
Janet Barone

Marketing & Events Manager
Kara Dornish

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
- 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

Thursday, July 21 – Saturday, July 23
NHF Annual Meeting
Orlando, FL

Sunday, July 24 – Thursday, July 28
World Federation of Hemophilia – World Congress
Orlando, FL

Thursday, August 4
WPCNHF Annual Meeting & Walk Kickoff
Pittsburgh, PA

Sunday, August 7 – Saturday, August 13
Camp Hot-to-Clot
Fombell, PA

Saturday, August 20
New Parent Network
Ligonier, PA

Saturday, September 17
Hemophilia Walk
North Park Boat House
Allison Park, PA

Saturday, September 17
Run For Their Lives 5K
North Park Boat House
Allison Park, PA

Saturday, September 17
Cornhole Tournament
North Park Boat House
Allison Park, PA

Saturday, October 8
Oktoberfest
Pittsburgh, PA

Sunday, October 30
Bowling Fundraiser
Neville Island, PA

Friday, November 11
New Parent Network
Erie, PA

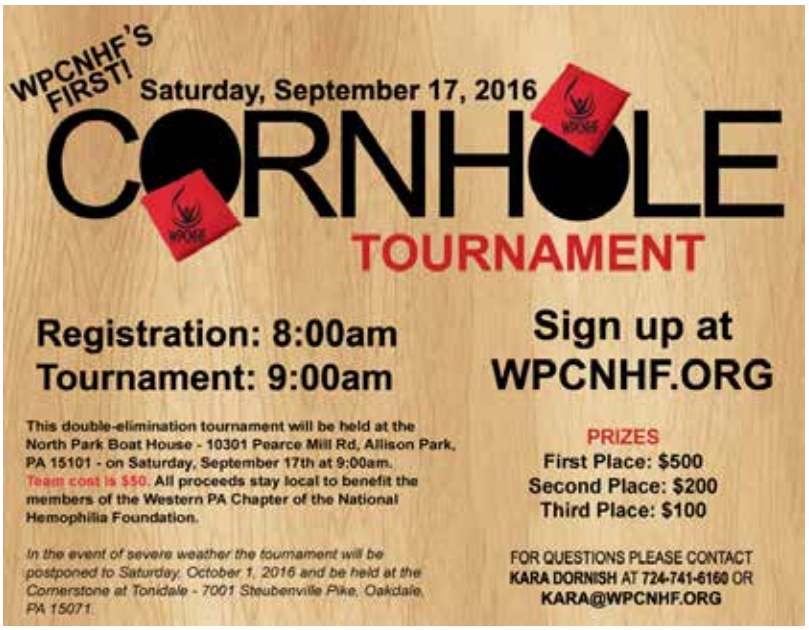
Saturday, November 12
Erie Fall Program
Erie, PA

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!

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

+ PROVEN PROPHYLAXIS

SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE

= *moments* YOUR WAY

Proven results with ADYNOVATE

+ **Zero median ABR** for joint or spontaneous bleeding episodes with ADYNOVATE prophylaxis†[1]

* ADYNOVATE allows you to infuse on the same 2 days every week.[1]

† Joint: 0.0 (Q1: 0.0; Q3: 2.0) median vs on-demand 38.1 (Q1: 24.5; Q3: 44.6); 2.9 (SD 8.0) mean vs on-demand 34.7 (SD 15.1). Spontaneous: 0.0 (Q1: 0.0; Q3: 2.2) median vs on-demand 21.6 (Q1: 11.2; Q3: 33.2); 2.9 (SD 7.1) mean vs on-demand 26.0 (SD 19.6).[1,2]

The safety, efficacy, and PK of ADYNOVATE were evaluated in a multicenter, open-label, prospective, nonrandomized, 2-arm clinical study (N=137) that compared the efficacy of a twice-weekly prophylactic treatment regimen to on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes.[1]

For patients 12 years and older with hemophilia A

To see if ADYNOVATE may be right for you, visit **www.ADYNOVATE.com**

ABR=annualized bleeding rate.

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

Indication

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

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

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

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

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

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

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

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

Please see following page for ADYNOVATE Important Facts.

References: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc.
2. Data on file. Baxalta Incorporated.

Baxalta

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

Important facts about

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

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

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

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

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

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

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

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

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

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.

How should I use ADYNOVATE? (cont'd)

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.

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.ADYNOVATE.com 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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Westlake Village, CA 91362 USA
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Issued 11/2015

15E001-ADY-US

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as i see it: A Letter to My Future Self

By Ian Muir

Dear Ian of 2026,

How is 40 treating you? I have high hopes that it's going great in multiple respects (house, job, dog, wife, etc.).

Of equal or greater importance, I hope that the next hemophilia treatment revolution is well under way. And I certainly hope that you're not taking anything resembling clotting factor concentrate, or for that matter any product that lasts less than four weeks to treat your hemophilia.

The years 2015 and 2016 were so hopeful, remember? You had been primed with knowledge, friends, and perspective from the Word Federation of Hemophilia Congress in Paris in 2012. Then, in 2015, you turned 30 and had a few mild health scares that reminded you of your own mortality. This set you off on a renewed quest of empathetic restlessness and searching. In 2015, novel approaches to treating hemophilia from some brilliant new players were being published, and the data looked promising. More accessible and effective treatment options were closer than the horizon for underserved people with inhibitors, and for some developing countries that lacked reliable access to any of the flavors of clotting factor. You felt excitement and hope every day (sometimes too much—do people still say you're too enthusiastic?), not only for you, but for your clotting-challenged friends and friends-to-be around the world.

What have you done with your new freedom to travel and be more "off the grid" when a single dose can last a month? I hope you've found time between stateside jobs to travel around the world and participate in preparing new markets that will do business with ambitious companies to expand access to hemophilia treatment. If all goes to plan, you should be far more concerned about what you're going to do with your now 12-year-old pit bull Charlotte for three months while hopping around the globe, rather than hassling with receiving $50,000 of clotting factor a month. I hope you only need a couple of doses of your current product. This should give you and your family some peace of mind to be abroad for several months at a time without needing to meet up with someone for a covert factor handoff or something. Just kidding.

I hope that your prediction has come true: that we have a new pace and standard for meaningful advances in improving quality of life for patients in developed and developing countries, with and without inhibitors. At the time, it seemed like a lot to ask, but I hope we were right about the capability of the bright minds in the companies that seemed almost ready to release—and community members that seemed almost ready to embrace—a revolutionary, game-changing product. Are you still as fond of analogies? Introduction of the iPhone, going to Mars, you couldn't quite decide which analogy would do justice, but I hope it has been all of those things and more.

Have we progressed, from only 20% of hemophilia patients treated globally to at least 50% now? I sure hope so. If not, please send word back to me in 2016 from your iPhone 16s, and I will rattle some extra cages for you.

Keep up the good fight,

Ian of 2016

(Continued on page 15)

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

THE FIRST 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

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: on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and routine prophylaxis to 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.

The most frequently occurring side effects of ELOCTATE are headache, rash, joint pain, muscle 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.

This information is not intended to replace discussions with your healthcare provider.

Biogen

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?
You can have an allergic reaction to ELOCTATE. 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. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

Common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

These are not the only possible side effects of ELOCTATE. Tell your healthcare provider about any side effect that bothers you or does not go away.

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.

44279-02

Manufactured by:
Biogen Inc.
Cambridge, MA 02142 USA
U.S. License # 1697

HCWP Corner

Things have been really busy at the Hemophilia Center of Western Pennsylvania recently…so busy that no one had time to write an article for the newsletter! Here's what has been going on there recently…

- The HCWP conducted 3 offsite clinics in June for benefit of Amish patients & families; they saw approximately 150 patients in 3 days, offered carrier testing for female relatives, attended by our own HCWP physicians and several CHP fellows & residents – which was a great experience for them. These clinics were also attended by several CHP dentists & fellows, which is very beneficial to patients, who don't have easy access to local dentists.
- Dr. Ragni was featured in special issue of a prestigious medical journal!
- We welcomed a new staff member, Carmen Knaus, Factor Program Specialist.
- Work with The Dartmouth Institute Microsystem Academy continues. The HCWP is the pilot site for a project focused on improving adolescent-to-adult transition.
- Camp Hot-to-Clot planning continues!
- The staff is getting training to use a new ultrasound machine that the HCWP will be purchasing this summer. This machine will help differentiate whether joint pain is related to a bleed or a different cause.
- Debbie Solvay & Walt Livingston attended Partners Basic program this Spring – training for clinical HTC staff
- Debbie Solvay attended HTC Nurse Coordinator training in May
- Many staff members will attend & speak at World Federation of Hemophilia Congress in July
- HAPPIEST NEWS: Kathaleen Schnur & her family welcomed baby Charlie on May 21. Everyone is doing well and Kathaleen will return to HCWP this summer after maternity leave.

Share Your E-mail Address with the Chapter

Are you receiving e-mail notifications regularly from the Chapter? If not, please consider sending us your e-mail address. We use e-mail to communicate time-sensitive information that would not be possible or cost-effective to send in a traditional mailing, such as opportunities to participate in paid phone or online surveys conducted by research and communication companies or opportunities to participate in online surveys conducted by the Chapter to help determine preferred locations and topics for our programs.

Please know that we do not share your e-mail address with other organizations. If you would like to be added to our e-mail list, please send an e-mail to **info@wpcnhf.org** and let us know.

Send us your e-mail address and you will receive:

- Program and special event invitations and updates
- Program registration reminders
- Notifications of scholarships and contests
- Survey opportunities, including:
  - Online surveys for Chapter program and event planning
  - NHF surveys for research or program planning
  - Notification of third-party paid surveys

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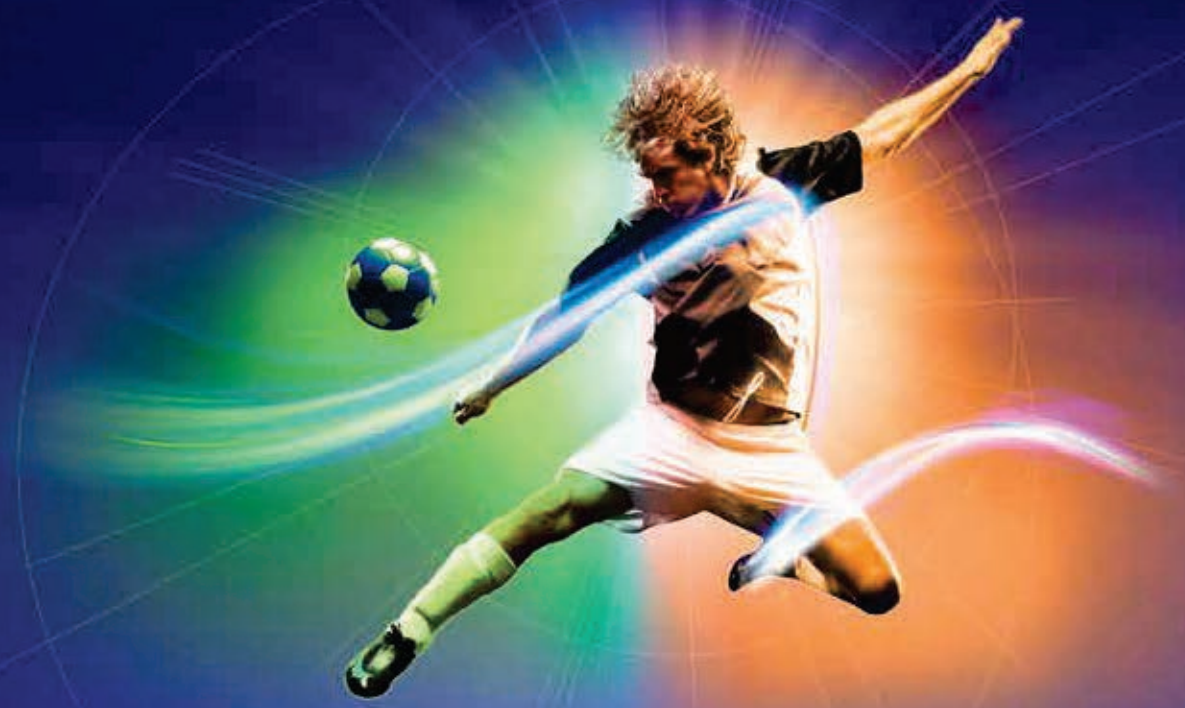

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www.CSLBehring-us.com **www.IDELVION.com** IDL16-03-0070 3/2016

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

Now Available!

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]

Want to Learn More?

Call 1-800-554-4440
for information about our **Free Trial Program**

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: 1/2016. NUW-016-CAD

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

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For the safe and optimal use of human proteins

2016 Hemophilia Walk Volunteer Opportunities

National Hemophilia Foundation Presents HEMOPHILIA walk '16 Every step makes a difference National Presenting Sponsor Baxalta

Set up - Arrive at 6:30 am - Help set up tables, chairs, and signage.

Run or Cornhole Registration & Check-In Staff - Arrive at 7:30 am – Help register onsite individuals and check-in already registered individuals.

Race Medals - Arrive at 8:00 am – Hand out race medals to runners as they cross the finish line.

Race Water - Arrive at 8:00 am – Stand along the race route and pass out water to the runners and walkers.

Chinese Auction - Arrive at 8:30am – Sell tickets for the Chinese auction.

Food Table - Arrive at 8:30am – Help set up food table and make sure area and kept clean.

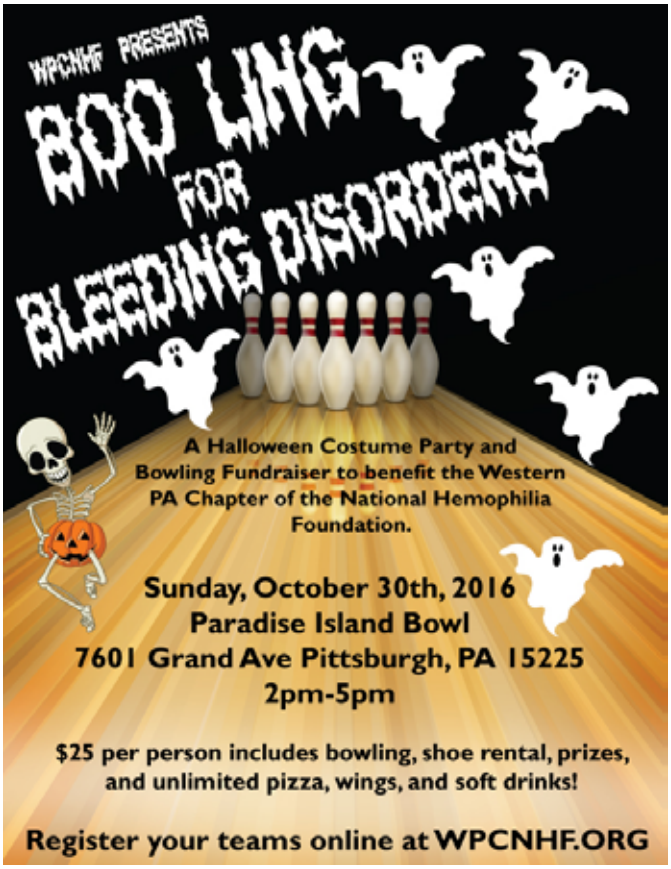
Walk Registration & Check-In Staff - Arrive at 8:30am – Help register onsite individuals and check-in already registered individuals.

T-Shirt Table Staff - Arrive at 8:30am – Organize and pass out Walk t-shirts.

Goodie Bag Table - Arrive at 8:30am – Pass out walk bags.

Clean up & Break Down Crew - Arrive by 11:30am – Help break down tables and chairs, clean up, and load up truck.

Please e-mail Kara Dornish at kara@wpcnhf.org or call 724-741-6160 to sign up for any of the above volunteer opportunities. We appreciate all help and would like to thank you in advance for your interest and support!!



EDUCATION DAY 2016

(Continued from cover page)

teenagers and camp staff gathered for an exciting Camp Academy program called Teachable Moments. This program was equally educational and entertaining! Anne Henningfeld and Judah Andrews from Beyond Recreation, presented this program, which is sponsored by Biogen. Anne presented challenging scenarios with campers and facilitated a discussion between the audience (who collectively played the role of a camp counselor) and Judah (who did an amazing job portraying different aged campers with different personalities). Together, the group learned how to take challenging situations and turn them into positive experiences for campers.

After lunch, Dawn Rotellini, chapter member and Sr. Vice President, Chapter Development & Education for the National Hemophilia Foundation, led a lively, impromptu discussion on what our members would like from the Chapter. Many great ideas were shared!

This day also included babysitting for young children, a delicious lunch buffet, and exhibits by our program sponsors. One member commented that the event was informative and her family always learns something new that they can apply to the daily management of their bleeding disorder. We thank our sponsors for making this event possible:

- Baxalta
- Bayer Healthcare
- Biogen
- BioRX
- Cottrill's Pharmacy
- CSL Behring
- CVS/Caremark
- Novo Nordisk
- Octapharma
- Option Care
- Pfizer

SPOTLIGHT ON THE MEMBER: MILLER FAMILY

(Continued from cover page)

disorder. At about 8 weeks old, Luke got his first bleed. We noticed a lump the size of a golf ball in his left cheek. Scott and I assumed he had some sort of infection so I took him to Children's Hospital North, while Scott stayed home with Sam. The doctor there was stumped and sent us to the Children's Main Campus emergency room. Once we arrived, the ER doctor decided to admit Luke for observation. After 5 days, Luke was discharged with antibiotics and a misdiagnosis. The bleed resolved on its own. When Luke was 6 months old, he started trying to crawl and he also started getting large bruises on his rib cage for no apparent reason. I took him to the pediatrician and he asked me if Scott or I had any family history of a bleeding disorder. Neither of us knew of any disorder, but the pediatrician ordered bloodwork to be safe. Two weeks later, we had our first visit to the Hemophilia Center of Western PA and learned that Luke had severe Hemophilia A. We've come a long way since that first visit and we still have a long way to go.

Since we had no experience with bleeding disorders, Scott and I were very overwhelmed. We just couldn't envision what Luke's diagnosis meant for his future or for our family's future. We are still learning every day. Our biggest struggle is finding a balance between allowing Luke to live a full life and knowing what activities are safe. The more he grows, the more we see how important it is for us to find the right balance. We continuously seek advice from the Hemophilia Center of Western PA and from other families. Even then, it feels like a lot of trial and error.

One of our favorite events is one the Center & Chapter holds jointly: Infusion Day. Nothing gave our family a greater sense of control over Luke's diagnosis than learning how to treat at home. Our family also participates in the Hemophilia Walk each fall. It has always been very important to us that Luke know he is surrounded by friends and family that will always be there for him. The Hemophilia Walk has been the perfect opportunity for us to gather all of his supporters in one place and enjoy a fun day.

The advice I would give any family new to the bleeding disorder community is that it's incredibly important to find a way to connect with other families. We have met families in the waiting room at the Center, at Chapter events and most recently at the Chapter's Tiny Tots program. The "Tiny Tots" events have helped us meet and spend time with other families with young children. In our most difficult moments, it's been other families who are affected by bleeding disorders that have offered the best support and advice. Never underestimate the knowledge that you can gain from others who are going on a similar journey.

as i see it: A LETTER TO MY FUTURE SELF

(Continued from page 7)

Ian is a 31-year-old who has severe hemophilia A, and has thankfully been in remission for hepatitis C genotype 1A for the past 12 years. Ian graduated from California Polytechnic State University, San Luis Obispo, and currently works in Cambridge, Massachusetts, as an IT and informatics strategy consultant for early-stage biotechnology startups. He lives in Arlington, Massachusetts, with his fiancée Katie and their adorable mutt, Charlotte. Ian enjoys rock climbing, riding his road bike, and running outside on sunny days. He hopes to participate in bringing about the next era of hemophilia treatment for his friends with inhibitors and those with inadequate access to factor around the world.

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- Spanish-speaking Case Specialists are also available

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8:00 AM-8:00 PM (ET) Monday-Friday. Spanish-speaking Case Specialists are also available.

*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Participation in the Free Trial Program is limited to 1 time only. This program is complimentary and is not an obligation to purchase or use a Bayer product in the future. Reselling or billing any third party for the free product is prohibited by law.

†The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

‡The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future product purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

§People with private, commercial health insurance may receive co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

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