



**Western Pennsylvania  
Chapter of the National  
Hemophilia Foundation**

*Spring 2016  
Inside this issue*

**Save the Date  
Hemophilia  
Walk**

**Run For  
Their Lives  
5K Run**

*See Page 11*

**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

# Hemogram

## PARENTS & TINY TOTS

Seven families joined us for the Parents & Tiny Tots program! This program, which was created specifically for parents of children with bleeding disorders, ages 6 and under, took place over two consecutive Sundays in March. This was the first of three events that will take place this year for the New Parent Network—an initiative created to provide new families with opportunities to learn more about their child’s bleeding disorder, as well as opportunities to network and build relationships with their peers. The Chapter worked closely with the Hemophilia Center of Western PA to bring the Parents & Tiny Tots program to the families.

Over the course of the two days, the parents learned about the basics of hemophilia and treating bleeds, different types of bleeds, precautions to take, trips to the ER, comfort positions, distraction techniques, and infusions. During the first day, a couple of experienced parents with older children



were on hand to share their experiences and answer questions. At the end of the first day, the parents assembled “Go Bags” to have on hand for Emergency Room visits and other urgent trips.

There was a lot of energy in the room on the second day! This day, the parents brought their adorable children with them. Babysitters watched over the children while the parents learned about comfort positions and infusions. The children then joined their parents and the families were able to practice comfort positions and roleplay the infusion process, with experts present.

*(Continued on page 15)*

## NACCHO REPORT

By Diane S. Standish, LSW

One very early, chilly, dark January morning, four Camp Hot-to-Clot staff members braved the outdoors, went to Pittsburgh Airport, and boarded a flight to sunny Tempe, Arizona to attend the North American Camping Conference for Hemophilia Organizations, better known by its acronym, NACCHO. This annual conference serves to kick off our camp planning process each year. It’s an energetic, creative, and dynamic “booster shot” to give us new ideas for camp themes, activities, and events.

This year, Janet Barone, Kim Ebsworth, Jackie Washington, and I attended. There were keynote sessions that we all attended, as well as small-group sessions on a multitude of camp-related topics. We tried to split ourselves up to attend as many of those as we



could. Some of the sessions targeted camp administrators and leaders, with topics like:

- Healthcare Guidelines at Camp
- Crisis Response
- Budgeting

Other sessions focused on practical and programming matters, such as:

- Cabin Management
- Fun, Educational Camp Games
- Intentional Storytelling

*(Continued on next page)*

## NACCHO REPORT

*(Continued from cover page)*

NACCHO is unlike any other conference I've ever attended. You don't sit for long; the presenters get you up and moving at many of the sessions. After we got back to Pittsburgh, the four of us talked about new ideas for camp that we got from NACCHO. We all thought of things we'd like to change or add to our camp program, although I can't tell you too much or it will spoil some surprises! Here are some hints:

- Enhanced camp staff training
- Arts & Crafts ideas
- Ideas for the Chapter's first-ever Family Camp 2016
- Theme, game and special event ideas for Camp Hot-to-Clot 2016

Camp Hot-to-Clot also received a big honor at NACCHO: 3rd place in the annual NACCHO Cup competition!! Prizes were awarded to five camp programs that met specific criteria. At Camp Hot-to-Clot in 2015, our teen campers, with the assistance of two young adult camp alumni, Tori Baker and Nikole Scappe, decided to make public service announcements (PSAs) to promote better understanding of bleeding disorders. The teens developed concepts for the PSAs, wrote scripts, decided who would play which characters, and with help from Tori, Nikole, and other camp staff, filmed and edited the PSAs, which are educational and funny! At NACCHO, we gave a brief presentation about this activity and showed the PSAs. Fellow conference participants voted on the top five, and

Camp Hot-to-Clot took the 3rd-place trophy (in my office; stop by and see it!), as well as \$1,000 for camp! We were so proud of our teen campers and all that they accomplished in a short time during camp last year. Check out the campers' award-winning PSAs on the Chapter website!

Camp Hot-to-Clot 2016 will be held August 7-13 at Camp Kon-o-Kwee in Fombell, PA, where we have held camp for the past seven years. We welcome campers who:

- Have an inherited bleeding disorder
- Have a sibling with an inherited bleeding disorder
- Are between the ages of 7-17 years

Registration opens May 2 and closes July 8.

## SPOTLIGHT ON THE MEMBER: MEET LASHELLE HEARDS

Lashelle Heards is a young, 23 year old woman living with von Willebrand Disease. She was raised, and still lives, in the Pittsburgh area. Although she wasn't diagnosed until she was a teenager, she says that looking back there were signs of a bleeding disorder. For example, throughout her childhood years, she had frequent, heavy nose bleeds; especially at night. The addition of humidifiers helped, but did not prevent the nose bleeds completely. When Lashelle got older, she experienced heavy menstrual periods (menorrhagia) that would last for weeks. Sometimes she experienced bleeding for months. Because she had relatives who have also experienced heavy bleeding, she thought it was normal for her family.

As a teenager, she missed a lot of school and felt embarrassed and weak from the bleeding. She worked hard to make up her school work. She took many of her required credits during her first two years of high school and despite missing so much school, she graduated on time.

It was during her high school years when

Lashelle was diagnosed with a bleeding disorder. She began to develop large, visible bruises on her arms and legs, which resulted from cheerleading. This was puzzling, though; she had never experienced this type of bruising before and she had been involved with cheerleading since the age of two! She hadn't begun any new activities, so she and her mother, Mary, became concerned. Her mother took her to see her primary care physician and she was later directed to the Hemophilia Center of Western PA (HCWP). The HCWP ran tests and Lashelle was diagnosed with von Willebrand Disease. She was approximately 15 years old at the time.

It took a long time to find a treatment option that was effective for Lashelle. In the meantime, she still experienced long periods. When she was approximately 16 years old, she participated in a research study for several months, for a potential new treatment for VWD. Eventually, she was able to manage her bleeding disorder with a combination of medications. In addition, DDAVP has also been effective for her, when needed.

Although Lashelle is now able to manage her von Willebrand Disease, she looks for opportunities to learn more about the bleeding disorder and attends Chapter programs whenever she can. She keeps busy between work and caring for her three-year-old son, DJ. She enjoys taking



him to the park where he loves to run around! They also enjoy listening to music and dancing. Lashelle is a graduate of South Hills and North Hills Beauty Academy and enjoys her work as a nail technician and beauty supplier.

Lashelle feels strongly that any woman who experiences problems with heavy bleeding should not assume that it's normal—even if their relatives have heavy bleeding. Just because the bleeding may not be life threatening, it doesn't mean there's not a problem. She recommends they get tested.

## Letter From The President, Nathan Rost

Dear Fellow members and Friends of WPCNHF,

I would like to take this time to thank Scott Miller for his 17 years of service to the Chapter, 6 of which he served as Board President. By all measures, WPCNHF has improved immensely on his watch with an increased budget, patient assistance, advocacy and educational programs.

From a personal point of view, your friendship and support have been very important to me and the board throughout the years. Your energy and dedication to the role will be hard to match, but you leave WPCNHF a better organization and a strong foundation for those who follow you.

It is my very great pleasure, on behalf of the Board and membership of WPCNHF as a whole, to thank you for your service and

the great work you have accomplished in your 6 years as Board President. We wish you the very best in your future endeavors and we look forward to any future involvement with WPCNHF.

Sincerely,

*Nathan Rost*  
WPCNHF Board President

## Letter From The Executive Director, Alison Yazer

Dear Chapter Members and Friends,

Happy Spring! The staff at the Chapter is busy planning our 2016 Calendar of Events and appreciate the feedback we have received through the needs assessment. If you haven't returned yours yet, please do so as soon as possible to assist us in making decisions about upcoming programming. We are here to

serve you, but we need to know where your interests lie in order to do that.

We're looking forward to our first ever Family Camp the weekend of June 10th-12th and hope that you plan to join us! Please check the Chapter calendar (on our website) and keep your eyes open for event invitations in the mail so you know when things are coming up!

As always, please contact the staff of WPCNHF with any questions or concerns. Thank you for all that you do on behalf of the bleeding disorders community.

Sincerely,

*Alison R. Yazer*  
Executive Director

### Board of Directors

**President**

Nathan Rost

**Treasurer**

Nick Vizzoca

**Secretary**

Mike Covert

**Board Member**

Matthew Suarez Pace, PhD., LMFT

### Staff

**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](mailto: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.

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

# Calendar of Upcoming Events

Saturday, April 16  
Education Day  
Cranberry Township, PA

Saturday, May 21  
Program TBD  
Altoona, PA

Friday, June 10 – Sunday, June 12  
Family Camp  
Hopwood, PA

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, 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

Saturday, November 12  
Erie Fall Program  
Erie, PA



## 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



## 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](mailto: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

*Ask us about sponsorship opportunities and how you can help!*

# INTRODUCING IDELVION NOW AVAILABLE



DELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC.  
IDELVION® is a registered trademark of CSL Behring Recombinant Facility AG.  
Biotherapies for Life® is a registered trademark of CSL Behring LLC.

©2016 CSL Behring LLC 1020 First Avenue, PO Box 61501,  
King of Prussia, PA 19406-0901 USA  
[www.CSLBehring-us.com](http://www.CSLBehring-us.com) [www.IDELVION.com](http://www.IDELVION.com) IDL16-03-0070 3/2016

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

# Iced Tees Winter Golf Outing

Our First Ever Iced Tees Winter Golf Outing was held at Diamond Run Golf Club in Sewickley, PA on February 20, 2016. Golfers arrived at Diamond Run at 9:00 a.m. and enjoyed an assortment of delicious little donuts donated by Peace, Love, and Little Donuts of Wexford. Each golfer received a t-shirt and goodie bag filled with an assortment of golf and winter weather items. Despite being prepared for the snow, at 60 degrees the day turned out to be warm and beautiful.

At 10:00 a.m. the golfers teed off for the 9 hole scramble. Mikey and Big Bob from the KISS Morning Freak Show joined in on the fun by riding around the course on a golf cart and checking in on the golfers as they made their way across the course. A tee sign was displayed at each hole containing a fact about Hemophilia or von Willebrand Disease.

A delicious soup and sandwich buffet was held immediately following the outing. A silent auction containing a wide range of Pittsburgh sports memorabilia and golf items was also held. Adam Morrison of Diamond Run hosted the awards and awards were given to the 1st, 2nd, and 3rd place teams as well as the closest to the pin, longest putt, and longest drive. KISS 96.1 DJ, Tall Cathy, joined us to present the winners of the auction items as well as thank all of our sponsors.

We are extremely grateful for all the golfers who participated as well as the donations we received from our Chapter members, our partner organizations, and other donors who offered their support. We are excited to report that over \$30,000 was raised from this event! 100% of this money will stay local to support the members of the Western PA Chapter of the National Hemophilia Foundation.

WPCNHF would like to thank all who participated in the event, sponsored the event, donated items, and all who volunteered their time to help make the event a success! We can't wait to see you all next year at the Second Annual Iced Tees Golf Outing!





2016 Iced Tees Sponsors



Ice Sponsors







Snow Sponsors





Tee Sponsor




In-Kind Sponsors






# Researchers Make Gene Therapy Breakthrough in Dogs with Factor VII Deficiency

In a recently published paper in the journal *Blood*, a team of researchers from the University of North Carolina (UNC) and The Children's Hospital of Philadelphia (CHOP) reported the successful application of gene therapy in dogs with factor VII (FVII) deficiency. This represents a significant advance, demonstrating the safety and efficacy of a novel therapy in large animal studies is a standard precursor to eventual clinical trials in humans.

FVII deficiency is a rare bleeding disorder with an incidence of 1 in 300,000 to 500,000, as both parents need to carry the gene in order to pass it on to their children. The condition, which affects men and women equally, is characterized by inadequate production of the FVII clotting protein. Babies are often diagnosed within the first six months of life after sustaining an intracranial hemorrhage or bleeding in the gastrointestinal tract. People with the

more severe form of FVII deficiency often experience joint and muscle bleeds, easy bruising and bleeds after surgery. Bleeding can also occur in the skin, mouth, nose and genitourinary tract, while women often experience severe menorrhagia (prolonged, heavy periods). The primary treatment for FVII deficiency is recombinant factor VIIa.

The study, "Sustained Correction of FVII Deficiency in Dogs Using AAV-Mediated Expression of Zymogen FVII," was published in the February 4, 2016 issue of *Blood*. The senior investigator was Paris Margaritis, D.Phil., head researcher at CHOP and Penn's Perelman School of Medicine. Leading the UNC team was Tim Nichols, MD, professor of medicine and pathology at the UNC School of Medicine.

For the study, Margaritis cloned the canine factor VII gene and enclosed that genetic material inside adeno-associated viruses (AAVs). These viruses act as delivery vehicles, or vectors, to carry the genetic material into living cells to sustain therapeutic effect without causing disease or triggering significant immune responses. In this case, the AAVs are designed to elicit the production of the FVII. Nichols and his colleagues then treated four FVII deficient dogs with a single injection of the therapy, administering different amounts of AAVs

in each of the animals.

They found that the amount of factor VII generated was directly proportional to the amount of AAVs given to the individual dogs. Nichols's team also monitored the dogs' progress over a period of three years and found that they all produced FVII levels that were sufficiently therapeutic – this is particularly encouraging for investigators as the amount of FVII necessary to achieve a sustained therapeutic effect in dogs correlates closely to that for humans. "This work is very exciting and promising," said Nichols. "The FVII-deficient dogs tolerated the initial gene therapy infusions very well and have had no adverse side effects over several years of follow up. In other related studies in dogs with hemophilia B (FIX), similar positive findings have translated to people with hemophilia B."

In addition, blood, kidney and liver function tests all showed that therapy was safe and did not trigger an unwanted immune response. The next step will be to conduct clinical trials in humans. "The table is now set to propose clinical trials that would treat people who suffer from FVII deficiency," concluded Nichols.

*Source: UNC Health Care news release dated January 20, 2016*

## Your IXINITY® Product Specialist, Grant Belsham

“Every day I am inspired by people in the bleeding disorders community—their energy, positivity, and support for each other make me proud to be a part of their lives.”

Let's talk about IXINITY and how you can get the most out of Emergent-sponsored programs, including the **Generation IX Project** and the **B More™ Scholarship Program**.



Contact Grant at 215.370.9818 or [gbelsham@ebsi.com](mailto:gbelsham@ebsi.com)



Manufactured by Cangene Corporation, a subsidiary of Emergent BioSolutions Inc. and distributed by Cangene bioPharma, Inc., a subsidiary of Emergent BioSolutions Inc.  
IXINITY [Coagulation Factor IX (Recombinant)], IXperience, B More, and any and all Emergent BioSolutions Inc. brand, product, service and feature names, logos, slogans are trademarks or registered trademarks of Emergent BioSolutions Inc. or its subsidiaries in the United States or other countries. All rights reserved.  
© 2015 Emergent BioSolutions Inc. IXI 136-0915



## 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](mailto: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](http://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.**

## **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

ELOCTATE® is a registered trademark of Biogen.

# Washington Days

Well over 300 people from the bleeding disorders community gathered in Washington D.C. for NHF's annual advocacy event, on February 25, 2016. Participants were easily recognizable on Capitol Hill, as participants of all ages were sporting a red tie! Why the red ties? March 2016 was designated as the first Bleeding Disorders Awareness Month with the goal of generating greater awareness of all inherited bleeding disorders including hemophilia, von Willebrand Disease, and other rare factor deficiencies. (This will ultimately lead to earlier diagnosis and the prevention of complications, unnecessary procedures, and disability.) NHF debuted it's Red Tie Challenge during Washington Days in an effort to rally the bleeding disorders community and its supporters to show their support for the designation of Bleeding Disorders Awareness Month.

Western Pennsylvania was represented by Victoria Baker, Nikole Scappe, Alison Yazer, Janet Barone, and Dawn Rotellini. We met with staff from the offices of Representative Mike Doyle and

Representative Keith Rothfus. We joined attendees from Eastern Pennsylvania for our meetings in the offices of Senator Bob Casey and Senator Patrick Toomey.

During each visit we talked about our experiences living with bleeding disorders and gave examples on how we and the bleeding disorders community, in general, have benefited from the federal hemophilia programs and initiatives supported by agencies of the Department of Health and Human Services. We asked for the funding to be maintained for these programs which include funding for services provided by hemophilia treatment centers, inhibitor prevention, and blood safety and surveillance.

In addition, we asked our representatives to co-sponsor HR3742, the Access to Marketplace Insurance Act (and asked our senators to introduce companion legislation), which would require health insurance companies to accept third party payments from nonprofit 501(c)(3) organizations. This would not only benefit people with bleeding disorders, but it would also benefit people living with a number of other rare, chronic and acute conditions.



This legislation would facilitate access to non-profit premium assistance to ensure that people in our community and others can rely on these programs to afford their health insurance.

Before leaving each meeting, we talked about the designation of Bleeding Disorders Awareness Month and asked our senators and representatives to take the Red Tie Challenge! More information on the Red Tie Challenge can be found at: <https://redtiechallenge.org/>



EDUCATION  
Advantage

## Scholarships for Our Community



**Education Advantage is open to students of all ages, regardless of which brand of treatment they use:**

- ▶ Hemophilia A (factor VIII deficiency), including those with inhibitors
- ▶ Hemophilia B (factor IX deficiency), including those with inhibitors
- ▶ Von Willebrand disease

**Three scholarship options:**

- ▶ \$7,000 University Scholarship to put towards your Bachelor's Degree
- ▶ \$1,000 Community College and Technical Scholarship
- ▶ One-time \$150 GED Assistance

Previous winners can apply to renew for 2016!

Apply before April 29th at  
[www.BaxaltaHematology.com/us/EA](http://www.BaxaltaHematology.com/us/EA)



# 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](http://www.hemophilia.org/walk) or contact: Kara Dornish, Local Walk Event Manager, at 724-741-6160 or [kara@wpcnhf.org](mailto:kara@wpcnhf.org).

[www.hemophilia.org/walk](http://www.hemophilia.org/walk)

Participate. Volunteer. Donate.



# Run For Their Lives 5K Run

A black silhouette of a person running with their arms raised in a celebratory gesture, splashing water. A red ribbon graphic curves across the bottom of the image.

To Register or Donate visit,  
<http://www.wpcnhf.org>

or e-mail  
[kara@wpcnhf.org](mailto: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

# Now Available!

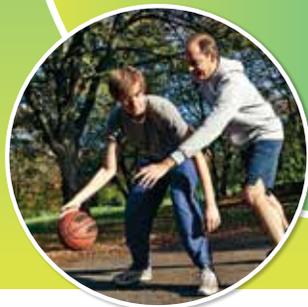
## For the Treatment of Adults and Children with Hemophilia A



# NUWIQ<sup>®</sup>

Antihemophilic Factor  
(Recombinant)

Because you are unique.



The First and Only  
Recombinant FVIII  
Produced in Human Cells  
Without Chemical  
Modification or Protein  
Fusion<sup>1-4</sup>

**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.

## 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:

$$\text{Required IU} = \text{body weight (kg)} \times \text{desired Factor VIII rise (\%)} (\text{IU/dL}) \times 0.5 (\text{IU/kg per IU/dL})$$

- 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](http://www.fda.gov/medwatch).**

### Manufactured by:

Octapharma AB  
Elersvägen 40  
SE-112 75, Sweden  
U.S. License No. 1646

### Distributed by:

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

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

Revised September 2015

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

**octapharma®**  
For the safe and optimal use of human proteins

## HCWP Corner

By Kathaleen Schnur, LSW

Happy Spring from the HCWP!

While this winter was milder than last, I think many of us are hopeful for longer days and sunnier skies!

We want to share with all of our patients and families that our Center was selected to participate in the ATHN Improvement Collaborative. As part of the National Hemophilia Program Coordinating Center (NHPCC) collaborative program, we joined nine other HTC's nationally to pilot this new program with training and guidance from The Dartmouth Institute Microsystem Academy. What this means for you, our patients and families, is you will begin to notice a more integrated and collaborative effort regarding transition. Since we are a lifespan clinic, we will be focusing our efforts on educating our patients to be independent with self-care and self-advocacy. We will be making an effort to reach out to families along the way for insight to our planning and processes.

While our entire Center is involved in the process, your core team consists of Kathaleen Schnur, Michelle Alabek, Cheri McShea, and Nancy Stinely.

The Center continues to improve patient and family experience through training and education for our HCWP staff and working collaboratively with the Chapter to share that training with our pediatric families.

If there is any interest of our patients or their families to participate in our Center's Consumer Advocacy Committee, our next meeting will be scheduled in May. Please contact Kathaleen at 412-209-7267 or Diane at 412-209-7286, to request an application.

As a reminder, please reach out to the Center as a resource for questions. Warmer weather means more outdoor activities and sports; remember to be proactive by wearing appropriate protective gear, wearing medical ID jewelry, and contacting the Center with any concerns. If your child needs a helmet, please contact Cheri McShea (Physical Therapist) as the HCWP has helmets on site to help with proper measuring.



## The Hemophilia Center of Western Pennsylvania

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

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

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

### Factor Program Services

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

### Patient Benefits

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

# PARENTS & TINY TOTS

*(Continued from cover page)*

(Comfort positions help keep children calm and help minimize movement during medical procedures.)

The children received Shadow Buddies®, which are condition specific dolls that are used to provide educational and emotional support to kids with chronic conditions. The Shadow Buddy that each child received has a “vein” in one arm. Along with their parents, the children practiced the infusion process on their Shadow Buddies using a toy medical kit and some basic, familiar

supplies such as alcohol swabs, gauze pads, and a fun assortment of Band-Aids®!

We thank the following speakers for participating in the program:

- Dr. Lynn Malec, HCWP
- Cheri McShea, PT, DPT, HCWP
- Kathaleen M. Schnur, LSW, HCWP
- Jake Wheatley, MS, CCLS, NCC, MT-BC, Child Life Specialist, Children’s Hospital of Pittsburgh
- Eileen Weinmann, RN, CPN, Pediatric Venipuncture Specialist
- Brianna Pace, Parent
- Janet Barone, Parent

In addition, we thank Nancy Stinely, RN, HCWP for volunteering her time to assist with the children and support the program.

We thank the following for supporting the New Parent Network with Educational Grants, Sponsorships, or Charitable Contributions:

- Baxalta
- Bayer Healthcare
- Biogen
- CSL Behring
- Emergent BioSolutions
- Novo Nordisk





**NOW AVAILABLE**  
**KOVALTRY<sup>®</sup>**  
Antihemophilic Factor (Recombinant)



Explore this new treatment at  
[www.KOVALTRY.com](http://www.KOVALTRY.com)



**Kovaltry<sup>®</sup>**

Antihemophilic Factor (Recombinant)

Bayer, the Bayer Cross, and KOVALTRY are registered trademarks of Bayer.  
© 2016 Bayer. All rights reserved.  
Printed in USA 03/16 PP-675-US-0143

**Western Pennsylvania Chapter of the National Hemophilia Foundation**

20411 Route 19, Unit 14

Cranberry Township, PA 16066

Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167

[info@westpennhemophilia.org](mailto:info@westpennhemophilia.org)

