Hemogram

WPCNHF

Western Pennsylvania
Chapter of the National
Hemophilia Foundation

Spring 2015
Inside this issue

REGISTRATION IS OPEN!

CAMP HOT-TO-CLOT

See Page 3

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 & PARENT RETREAT

WPCNHF held its first-ever Teen and Parent Retreat on March 20-22 at the Family Resources Retreat Center in Mars, PA! Patrick Torrey, Founder of GutMonkey and Eric Hamblen, Co-Founder and Program Director of PACE, Inc. and PACE Place, custom-designed and facilitated a weekend program specifically for the WPCNHF Teen and Parent Retreat. Throughout the weekend, the group worked toward creating individual family goals to move toward improved healthcare independence and improved life skills for general independence. Together, the group worked through a process and created a contract as part of their commitment to improve communication and achieve their goals.

The group also heard from Nayan Heath, Nurse Educator Specialist with Pfizer Hemophilia. Nayan presented the program Constructive Communications, which kicked off the weekend retreat. In addition, the teens also attended a program with Nikole Scappe, NHF National Youth Leadership Institute (NYLI) member and WPCNHF Advocacy Intern, and Diane Standish, LSW, from the Hemophilia Center of Western PA. The group discussed life skills and then the teens gave their opinions and advice on how to deal with specific scenarios which addressed social media, bullying (viral and physical), alcohol, drugs, and drunk driving. They also worked through a decision making activity which tested their negotiation and ethical skills. The weekend also included bonfires and optional outdoor activities.

We would like to thank the sponsors of the WPCNHF Teen & Parent Retreat. Without them, the weekend would not have been possible:

- Colburn-Keenan Foundation
- Hemophilia Center of Western PA
- Pfizer Hemophilia

We would also like to thank Tori Baker, NHF NYLI member, for joining us and volunteering her time over the weekend.

Teen & Parent Retreat Planning Committee: Janet Barone, WPCNHF Member Services Manager, Diane Standish, LSW, HCWP, Kathaleen Manns-Schnur, LSW, HCWP, Nikole Scappe, WPCNHF Intern and NHF NYLI


Huge Cube

Letter From The President, Scott Miller

Each year, we start with some great programs and events. I am so thankful that our staff is so conscious of the needs of our members and continues to try to be responsive to their needs for programs, patient assistance, and other requests that come in every day. Over the last several years, we have matured as a Chapter and are providing such a high level of service – I want to thank the staff and all of our wonderful volunteers for their hard work.

The 3rd Annual Bowling for Bleeding Disorders is coming up next month – one of our three main fundraisers for the year. Please tell your friends about it. As with all of our fundraisers, we continue to use these events to increase awareness of bleeding disorders. I am continually amazed how often we have an event and an individual approaches the staff to discuss an issue with a family member. The next thing you know, we discover their family is impacted by bleeding disorders and they are an active member who is participating in chapter activities! Our efforts continue to bolster not only our financial condition, to allow us to provide high quality service, but our reputation and recognition in Western Pennsylvania.

As the chapter embarks upon the first year of its new strategic plan, you will see us continue to work to maintain relevance in your lives and in the lives of our members. We continue to not only work to increase our services, but our recognition. Visit our new url at http://www.wpcnhf.org for additional information on events. As always, please feel free to contact Alison or Janet with any ideas you have for programs. We would love to hear from you with your thoughts and ideas of what we might do to fulfill our mission of making your lives better through education, advocacy, resource and referral.

As the snow tries to melt and summer approaches, I am looking forward to another wonderful year as the Chapter continues to serve our community. As always, feel free to contact the office with any questions or concerns you have. We are here to be a resource for you; therefore, you should never hesitate to call.

Sincerely,

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

Letter From The Executive Director, Alison Yazer

Dear Chapter Members and Friends,

I hope that 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 attend the events that will take place in the coming months. Our fourth annual Infusion Day took place in March in conjunction with the Hemophilia Center staff and it was the best attended Infusion Day to date! We hope to continue this event each year and we want to let you know that the event is for all superheroes – patients, moms, dads, grandparents, siblings, babysitters, and neighbors all found value in this event. The nonthreatening and lighthearted atmosphere made everyone feel welcome, no matter the skill level. I would like to offer a heartfelt thanks to the superhero staff of HCWP for their hard work on this great event. Their dedication to the bleeding disorders community does not go unnoticed.

I would like to welcome Melanie Holcomb to the Chapter as our new Fundraising & Events Manager. If you see her at an event, be sure to offer your warm welcome! Melanie comes to WPCNHF with a background in event planning and execution so I'm sure she'll accomplish great things for us!

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

CAMP HOT-TO-CLOT

REGISTRATION IS OPEN!

We cannot make exceptions to the deadlines, so please complete your child's registration ASAP. If you need paper forms or have any questions, please contact Michelle Alabek at the Hemophilia Center of Western PA.

Phone: 412-209-7292 • E-mail: malabek@itxm.org

Please visit our registration website: www.campdoc.com

REGISTRATION CLOSES FRIDAY, MAY 8.

ALL MEDICAL AND HEALTH CARE PROVIDER FORMS MUST BE SUBMITTED BY FRIDAY, MAY 22.

Calendar of Upcoming Events

Monday, April 20
State Advocacy Day
Harrisburg, PA

Monday, April 27
Food & Fitness
Robinson Township, PA

Sunday, May 3
Bowling for Bleeding Disorders
Pittsburgh, PA

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

Saturday, June 27
Dental Care
Pittsburgh, PA

Thursday, July 23
WPCNHF Annual Meeting
Homestead, PA

Saturday, August 1
Self Care for Caregivers
Location TBD

Saturday, August 29
Cracking Code (DNA)
Power of Empowerment
Erie, PA

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

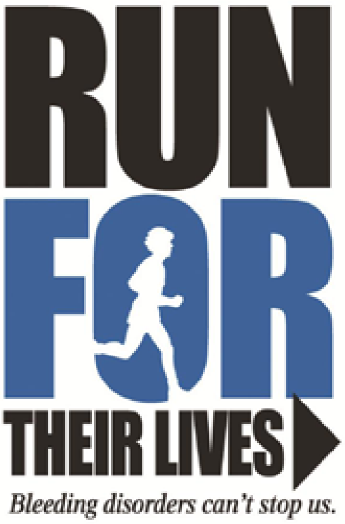
Saturday, September 12
Run for Their Lives
North Park, Allison Park, PA

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.

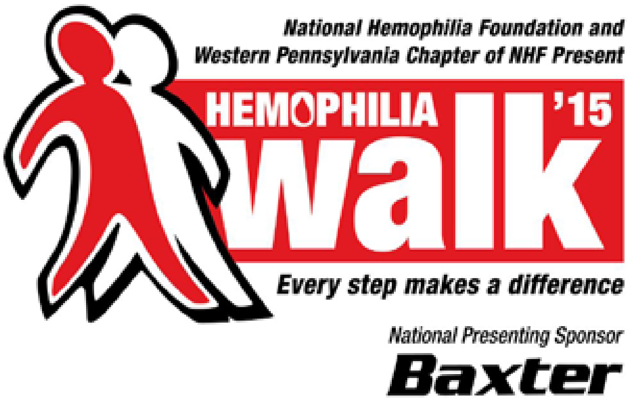
WPCNHF CFC Number is: 81343



Benefitting
The Western Pennsylvania Chapter of
the National Hemophilia Foundation

5K Run

September 12, 2015
Race begins at 8:30 am
Harmar Grove Shelter, North Park
724-741-6160 or Melanie@wpcnhf.org



SAVE THE DATE 9/12/15

Join us to support the Hemophilia 5K Walk! We will walk to raise **critical FUNDS and AWARENESS** for the bleeding disorders community. Your support is greatly appreciated!

Saturday, September 12th Walk Start Time: 10:00am

North Park. Harmar Grove Shelter, South Ridge Dr.
Allison Park, PA 15101

To register please visit www.hemophilia.org/walk or contact: Melanie Holcomb, Walk Event Manager, at 724-741-6160 or melanie@wpcnhf.org

Ask us about sponsorship opportunities and how you can help!

BAXTER'S COPAY ASSISTANCE PROGRAM

Are you eligible to save up to $12,000 every 12 months?

Introducing CoPay assistance designed for you.

Let us help pay for your medication in 3 simple steps.

1. Call us at 1-888-BAXTER-9 (1-888-229-8379).
2. Answer a few simple questions, and let Baxter handle the rest.
3. Receive eligibility information in the mail.

*Full terms and conditions apply

We've got you covered.

Call 1-888-BAXTER9 (1-888-229-8379) or visit www.hemophiliasupport.com.

Personalized support

Baxter recognizes the importance of helping you meet the challenges that life presents. Visit us at www.nava.baxter.com for a variety of resources, assistance, and individual support for living with hemophilia.

September 2014 USBS/MG155/14-0044

Baxter

Greetings from the HCWP!

We hope all of our patients and their families are thawing out from this long winter.

We would like to formally welcome Cynthia Ventrone to our team as our Medical Assistant. Cynthia has worked in the medical field for over 20 years. Cynthia enjoys the outdoors, exploring museums, and attending performances both in the city and supporting the local high schools. We would also like to welcome Tom Peterson as our Factor Program Specialist. Tom brings 20 years of pharmaceutical experience. Tom is a devoted father who spends much of his time outside of work transporting and cheering his kids on at their respective sporting events.

We would like to thank all of our patients and their families for their patience during our transitions here at HCWP. We recognize and respect that change can be difficult, but we are committed to continuing to provide quality, comprehensive care to our patients and their families. We appreciate your support, concern, and dialogue. We continue to encourage all of you to communicate with us either directly, through the patient satisfaction survey, or through your participation our Consumer Advocacy Committee.

Please remember the importance of committing to your own health by maintaining your well visits at the HCWP. If your diagnosis is moderate to severe, you should be seen by your hematologist at least once per year. If you have a milder diagnosis you should be seen at least every other year. The importance of well visits is to review your current health and history as it applies to your hemophilia or other inherited coagulation disorders, counsel about ways to improve your health, and an exam tailored to your preventive care needs. HCWP is always available for acute needs or assessments as well.

NHF's 66th Annual Meeting

By: Valerie Conrad-White

My name is Valerie Conrad-White, I have Von Willebrand's disease. My son, age 20, and my mother, recently deceased, also have the same bleeding disorder. My family recently had the opportunity to attend the NHF Annual meeting in Washington D.C. with the financial help from the W. PA Chapter of NHF. We attended many sessions appealing to all of us, as a family, and some just for me, as a woman.

We spent most of our days either in the sessions learning new things or in the exhibit hall talking with vendors about their products. Everyone was very friendly and was open to discussing all things dealing with bleeding disorders. I met a lot of new people and had a chance to get reacquainted with some old friends. Carson, my youngest son, had a great time in the exhibit hall. There were so many hands on activities to peak his interest and get him involved. He loved all the vendors and the variety of giveaways. One of our favorite activities in the exhibit hall was writing our wishes on balloon tags. Then on our last day we joined together with other families and released the balloons with our wishes up into the heavens. We watched them float away until we could no longer see them amongst the clouds.

Our evenings were filled with family events. One evening we were bused to the National Zoo where we ate a dinner beside the lions and their cubs. We watched them play as we ate a buffet dinner. After dinner we completed a scavenger hunt throughout the zoo with the guidance of volunteers and some friends we met along the way. Another night we were treated to a private tour of the air and space museum. We munched on desserts and walked among the different air crafts and space vessels. We even got to end our night with an astronaut.

The experience was both very beneficial and educational. We were thrilled with the entertainment provided and the knowledge of the individuals hosting the sessions. My family is looking forward at attending another annual meeting in the near future.

NHF Annual Meeting Grant

WPCNHF is pleased to offer Educational Grants to attend NHF's 67th Annual Meeting in Dallas, TX, on August 13-15. If you'd like to receive an application, please contact the Chapter and we will be glad to send you one. Applications can also be downloaded from the Chapter's website.

Infusion Day

Over 50 people attended Infusion Day this year! We thank the nurses and other staff from the Hemophilia Center of Western PA for staffing the learning stations and creating a fun,super hero theme for the event!

Learning stations included finding good veins, practicing infusion with a fake vein using a BayCuff™ self-infusion training kit, and learning how to access a real vein. A coloring station was set up for children to color their own super hero masks! In addition, Factor Manufacturer and Home Healthcare representatives were present to give participants an opportunity to mix sample factor products and to learn about home healthcare services.

(Continued on page 15)

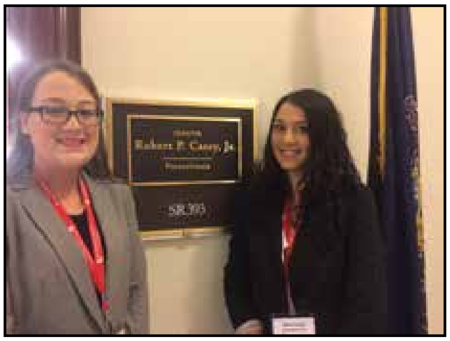
Washington Days 2015

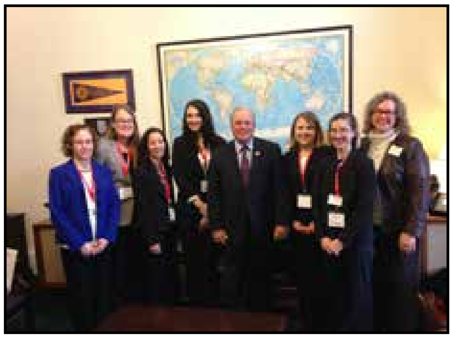
By: Tori Baker

Washington Days, held on February 26, 2015 had a total of about 300 participants from across the United States and Puerto Rico. It was a very amazing experience. Participants ranged from children who are affected with bleeding disorders, to those over 65 who have been active in the community since they or their loved ones have been diagnosed. Each one of the attendees had a story to tell and I wish I could have heard them all. The stories from the older generation show how far we have come as a community to improve both quality of life and treatment options for those affected with hemophilia, von Willebrand's disease, or any other bleeding disorder.

The late Robin Williams once said, "No matter what people tell you, words and ideas can change the world." I believe this quote is relevant to my time on the Hill for Washington Days. When we work together as a community on a national level to discuss issues on legislation,positive changes can result. It is important that we as a community stay knowledgeable in legislation decisions that can affect our quality of health in the future.

As a first time attendee at Washington Days I was both excited and intimidated at the thought of talking to the state representatives and senators (or in some cases their legislative correspondents). I was apart of a team of familiar faces which helped alleviate some of my nerves. Prior to our meetings, we discussed how each member would contribute in our conversation with the representatives and senators. When I was asked how I would contribute, I was suggested to speak about my personal experience with my bleeding disorder; at this, I was stumped. How was I supposed to share my story, when I didn't even think I had a story to share?





I was diagnosed with VWD type I when I was younger, but really didn't have any issues, other than requiring DDAVP prior to surgeries. After some thought, I decided to share my sister, Allison's story. Allison, who also has VWD type I, has to treat monthly with Humate P,

(Continued on page 15)

3rd Annual Bowling Marathon

Spare an afternoon to *Strike* out bleeding disorders

Starting on April 1st, you can register online. No joke! It's a 30 day fundraising campaign.

Here's how it works:

- Register online as an Individual or get a few friends together as a Team. All ages are welcome. The more the merrier! The registration fee is $25 per person.
- Send out emails to friends & family asking them to contribute to your bowling fundraiser. They can donate easily online! We'll send you sample letters for easy fundraising.
- Join us for a fun afternoon of bowling, FREE pizza, wings, soft drinks & a T-shirt!
- Accept your award for "Lowest Score", "Hall of Fame Fundraiser", or "Style to Spare"?

Visit our New website www.wpcnhf.org and look for the link to Register as Individual or Team. You can also register by contacting Melanie at 724-741-6160 or melanie@wpcnhf.org.

Thank you for your ongoing support of our fundraising efforts to benefit the members of the WPCNHF chapter. Every dollar makes a difference! We were able to honor every request for patient assistance last year and expand our education outreach in underserved areas due to your support. Let's keep it up, *we're on a Roll*!

Sunday, May 3rd from
2:00 – 5:00 pm
Paradise Island Bowl
7601 Grand Ave. Neville Island, PA 15225

WPCNHF Scholarship

Applications are available for the $2,500 WPCNHF Scholarship, for the 2015-2016 school year. Any student or immediate family member of a person with hemophilia, von Willebrand Disease, or a related inherited bleeding disorder is eligible to apply for this scholarship, as long as he/she meets the criteria. Please contact the Chapter if you'd like to receive an application or download a copy of the application from our website. Completed applications must be postmarked by June 30, 2015.

Scholarship Workshop

Fourteen members attended the Bleeding Disorder Educational Scholarship Workshop held on February 7, in the computer lab at the Regional Learning Alliance, in Cranberry Township, PA.

The program opened with guest presenter Wendy Dunlap from the Pennsylvania Higher Education Assistance Agency, PHEAA. Wendy gave an informative presentation that covered funding opportunities and tips for applying for financial aid.

Next, Tony Tezak, from Cottrill's Pharmacy, presented the Bleeding Disorder Scholarship Workshop, which he developed. His program included the importance of writing a winning scholarship essay and the importance of completing and submitting applications accurately. He also discussed the WPCNHF Scholarship, during his program.

The program wrapped up with Nikole Scappe, winner of the 2014 WPCNHF Scholarship, talking about college life, balancing work and college, her experiences in the bleeding disorders community, and how your volunteer experiences can benefit you when applying for scholarships.

We would like to thank Cottrill's Pharmacy and Bayer HealthCare for sponsoring this program.

2014 WPCNHF Scholarship Winner

My name is Nikole Scappe and last year I was chosen as the recipient for WPCNHF's scholarship. I am currently a sophomore at La Roche College double majoring in Marketing and Management. Since I was fortunate enough to receive the scholarship, I have been able to buy a new laptop and cover the cost of my books for the fall semester. If you are or were a college student, you understand how costly books can be. I look forward to reciprocating the incredible gift the Chapter has bestowed upon me. I will continue working with NHF and the Chapter to create more educational outreach and advocacy programs. I wish all of you who are applying for the scholarship the best of luck.

Spotlight on the Member: Baker Family

When Victoria (Tori) Baker, now 21, was born, her parents, Jack and Rebecca, weren't familiar with bleeding disorders and Tori didn't show any signs of having a bleeding disorder. In fact, it was treatment for another condition, sleep apnea, which ultimately led to the unexpected discovery of a bleeding disorder. When she was a toddler, her parents noticed that she was not breathing properly when she was asleep. They were very concerned and took their daughter to the doctors to find out what was wrong. In the end, Tori was seen by several doctors and had a total of six sleep studies, at three different locations. However, the results all came back normal. So her mother videotaped her when she saw her breathing abnormally and showed the tape to a pulmonologist at one of the hospitals. The doctor told the Bakers that Victoria was in the final stages of sleep apnea. Now that they knew what was happening, they needed to find out why. After a few more appointments with specialists and a second opinion, it was determined that Tori's tonsils were causing the problem and they needed to be removed. Her tonsils were enlarged, and they would collapse and close off her airway when she was sleeping or resting.

In preparation for the surgery, Tori had routine, pre-op blood work completed. This blood work led to the discovery of von Willebrand Disease (VWD). The Bakers were not familiar with VWD and were very concerned upon first hearing the diagnosis. As an infant, Tori had numerous blood transfusions and they were fearful this was somehow connected. They soon learned, though, that this was something with which she was born.

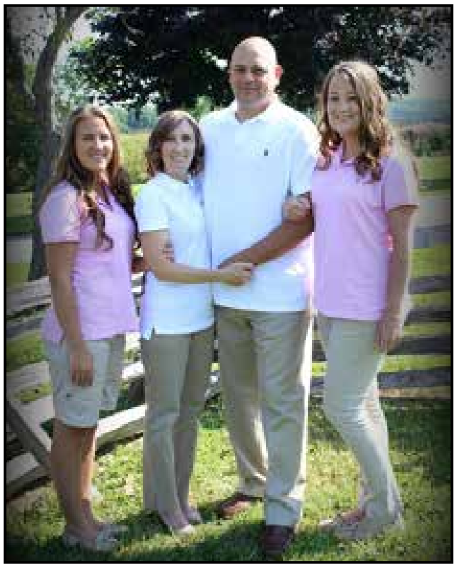
The Bakers were referred to the Hemophilia Center of Western Pennsylvania (HCWP) and further testing confirmed the diagnosis: Type 1 von Willebrand Disease. After family testing, Jack was also diagnosed. He had never had any complications and, therefore, had never been previously diagnosed. (And since learning of his diagnosis, he still has never had any bleeding issues.) Tori was given a DDAVP challenge, which was successful. The family proceeded with Tori's surgery and she was treated with DDAVP.

A few years later, another daughter, Allison (Allie), joined the Baker family! When Allie was about five years old, she also needed to have her tonsils removed. In preparation, she was tested at the HCWP to find out if she also had VWD. The results came back with the same diagnosis as her sister. Allison was treated with DDAVP and didn't have any complications from the surgery.

As the years went on, Tori did fine and did not have any significant bleeding issues. She only needed to be treated with DDAVP prior to any surgeries. Allie, on the other hand, has had her share of bleeds that required treatment. When Allie was 11 years old, she experienced her first joint bleed after playing soccer. And when she hit puberty, she hemorrhaged for 11 weeks. This time, the DDAVP was not effective and she had adverse reactions to hormone therapy. Therefore, Allie needs to infuse with factor to control bleeding and as a preventative measure when she has dental work.

Rebecca learned about the Chapter through a friend and has been a member for approximately 10 years. In the beginning, the family attended many educational events. She was glad her daughters had opportunities to be around other kids with bleeding disorders. The family developed friendships with others in the community and received a lot of support. She was especially impressed with how the kids in the community supported each other.

The girls soon began attending camp and their circle of friends grew even more! Rebecca said the kids at camp consider themselves brothers and sisters and they continue to support each other outside of camp. They have mourned losses together and have helped each other in times of need. They have gone through a lot together and have learned a lot about life. Allie has attended Camp Hot-to-Clot and Camp HemoVon. Tori has attended Camp Hot-to-Clot, where she was an LIT (Leader-in-Training). She then went on to become a Camp counselor. This summer, Allie is completing her second year as an LIT at Camp Hot-to-Clot.



Tori, who is now a Senior at Slippery Rock University, is a member of the National Youth Leadership Institute (NYLI) at the National Hemophilia Foundation. NYLI provides youth in the bleeding disorders community with leadership opportunities to effect change and positively influence others. There's an application process and members can remain in the program for three years. Within the past year, Tori has served as a Chapter volunteer with teen programs, including the recent Teen & Parent Retreat. She is also planning to volunteer at Camp Hot-to-Clot this year.

Rebecca has also volunteered her time with the Chapter and has helped the staff with various office tasks. She has also been trained as a facilitator for NHF Next Steps programs (programs targeted at youth between the ages of 9-15, who have bleeding disorders), and has helped put together a program for girls with bleeding disorders and their mothers.

In addition to participating in many educational programs, the family has also supported the Chapter's advocacy events. Rebecca has participated in Harrisburg Days, our annual state advocacy day. Tori participated in Washington Days for the first time this year and shared her family's story when we visited the offices of our senator and representatives. We were proud to have her on our team! (See Tori's Washington Days article in this issue.)

Rebecca suggests that people living with bleeding disorders, whether newly diagnosed or not, would benefit from participating in events in the bleeding disorders community as much as possible. She recommends finding people with similar interests and talk with them about what best works for them. If you are new to bleeding disorders or entering a new stage in your life, it can be very helpful to have a mentor. (For those interested, the Chapter and the HCWP can help you find a mentor.)

ALPROLIX™
[Coagulation Factor IX (Recombinant), Fc Fusion Protein]

A treatment for hemophilia B

PROTECTION* FROM BLEEDS

Starting with at least a week between prophylaxis infusions

Dosing regimen can be adjusted based on individual response.

*Protection is the prevention of bleeding episodes using a prophylaxis regimen.

To learn more, contact CoRe Manager **Christine Rowe** at **christine.rowe@biogenidec.com** or call **267-249-8372.**

INDICATIONS AND IMPORTANT SAFETY INFORMATION

Indications

ALPROLIX, Coagulation Factor IX (Recombinant), Fc Fusion Protein, is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

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

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important safety information

Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

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 and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. 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 ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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

biogen idec.

FIX-1007929 09/2014

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX™ /all' pro liks/
[Coagulation Factor IX (Recombinant),
Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX™ 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 ALPROLIX™?

ALPROLIX™ is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is a so called congenital Factor IX deficiency.

Your healthcare provider may give you ALPROLIX™ when you have surgery.

Who should not use ALPROLIX™?

You should not use ALPROLIX™ if you are allergic to ALPROLIX™ or any of the other ingredients in ALPROLIX™. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX™.

What should I tell my healthcare provider before using ALPROLIX™?

Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX™ may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX™ passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX™ may not work for you).

How should I use ALPROLIX™?

ALPROLIX™ should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX™ by themselves or with the help of a family member.

See the Instructions for Use for directions on infusing ALPROLIX ™. The steps in the Instructions for Use are general guidelines for using ALPROLIX™. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider.

Do not use ALPROLIX™ as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX™.

What are the possible side effects of ALPROLIX™?

Common side effects of ALPROLIX™ include headache and abnormal sensation in the mouth.

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

ALPROLIX™ may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, "inhibitors," against ALPROLIX™, which may stop ALPROLIX™ from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX™.Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX™?

Store ALPROLIX™ vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX™ vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX™ at room temperature:

- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it, not return the product to the refrigerator.
- Do not use product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX™ if the reconstituted solutionis cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX™?

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

Manufactured by
Biogen Idec Inc.
14 Cambridge Center
Cambridge, MA 02142
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Gene Therapy Study in Dogs Shows Markedly Lower Bleeding Rates

In a recently published paper, an international team of researchers report effectively administering gene therapy to three dogs with hemophilia B in an ongoing study. The report, "Liver-Directed Lentiviral Gene Therapy in a Dog Model of Hemophilia B," was published March 4, 2015, in the journal Science Translational Medicine. The lead author of the paper was Luigi Naldini, MD, PhD, director of the San Raffaele Telethon Institute for Gene Therapy at the San Raffaele Scientific Institute in Milan, Italy.

The three dogs in the study were administered the genetherapy either through direct injection into the liver, a primary source of clotting factor protein production, or intravenously. The therapy was housed in repurposed retroviruses called lentiviral vectors. These vectors act as vehicles, carrying customized genetic material to elicit the production of factor IX (FIX). One advantage in using lentiviruses is that a majority of patients do not generate antibodies to this type of vector, avoiding an immune response that would otherwise render the treatment ineffective. Another benefit of using lentiviral vectors is their large size, enabling them to deliver greater concentrations of the FIX gene, resulting in a more optimal therapeutic effect.

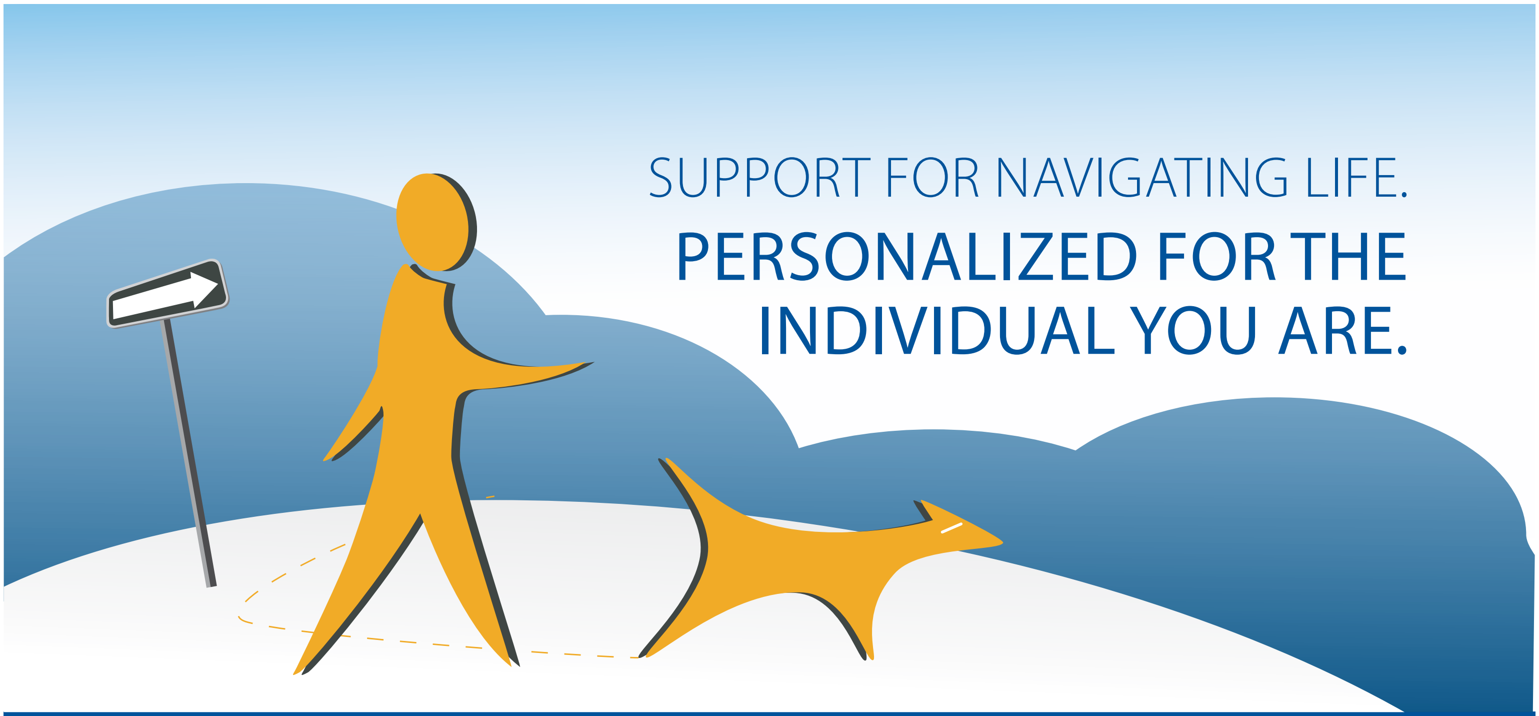
Three years after administering the treatment, Naldini and his colleagues report significant symptomatic improvement. Prior to receiving the therapy, the dogs experienced approximately five spontaneous bleeds per year. In contrast, in the three years since receiving therapy, the dogs have averaged 0 to 1 bleed per year. This notable decrease in spontaneous bleeding events was achieved because the gene therapy boosted FIX generation in the dogs from virtually 0 to 1%-3%.This seemingly modest increase was enough to dramatically lower bleeding rates.

"The result was stunning," said Timothy Nichols, MD, director of the Francis Owen Blood Research Laboratory at the University of North Carolina School of Medicine and co-senior author of the paper. "Just a small amount of new factor IX necessary for proper clotting produced a major reduction in bleeding events. It was extraordinarily powerful."

Investigators have also reported no harmful side effects. Safety being a primary concern, Naldini and his team performed additional studies in types of mice that are more likely to develop complications from lentiviruses, such as malignancies. No hazardous responses to the therapy were reported. "Considering the mouse model data and the absence of detectable genotoxicity during long-term expression in the hemophilia B dogs, the lentiviral vectors have a very encouraging safety profile in this case," said Nichols.

Ideally, Naldini, Nichols and their team would like to increase FIX production to 5%-10% to essentially eradicate spontaneous bleeding in patients with hemophilia B. To reach this endpoint, several years of additional investigation, including larger animal studies and eventual human clinical trials, will need to occur.

Source: ScienceDaily, March 12, 2015



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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.

Our Mission:

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

WPCNHF Wish List

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

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

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Infusion Day

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We would like to thank our Infusion Day sponsors:

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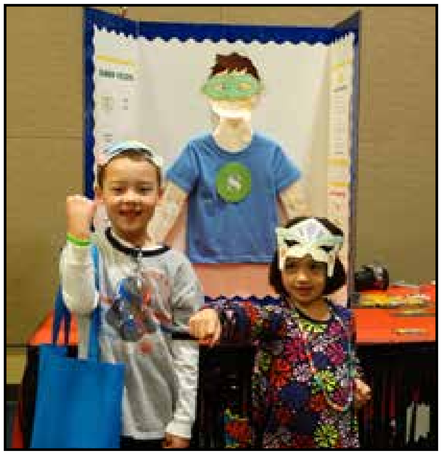

Washington Days 2015

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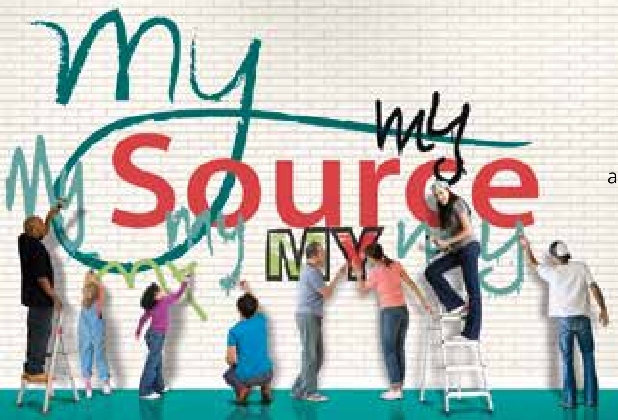
which is made from human blood product. With this, I addressed the importance of blood safety and proper screening. Currently the CDC division of blood disorders allocates $5 million dollars for blood surveillance and prevention along with HTC research. As a team we requested that funding to be maintained to monitor blood and blood product safety in the bleeding disorder community along with the general population who also relies on the blood supply for other purposes.

This year, the National Hemophilia Foundation selected three issues to discuss with the representatives and senators on the Hill. These three issues included maintaining funds for Federal Hemophilia Programs, access to skilled nursing facilities or SNFs for patients with hemophilia, and the co-sponsoring or companion legislation of the Patients' Access to Treatments Act or PATA. To learn more about any of these topics that were presented for legislation please feel free to contact a Chapter staff member.

Looking back at my experience on the Hill, I feel like I made a difference in the bleeding disorder community. I feel that it is an important event to participate in for anyone affected with a bleeding disorder whether patient, caretaker, family, or friend. It doesn't matter the age, young or old, you have a story to share and your voice does matter!



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