Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Winter 2015

Inside this issue

SAVE THE DATE

Harrisburg Advocacy Day

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**

YOUTH WINS TOURNAMENT AND $2,500 FOR WPCNHF!

My name is Will McCarthy. I am 12 years old, I like to golf, play Frisbee and baseball, I can solve the Rubik's cube in about 30 seconds, and I have moderate Hemophilia B.

This year I attended the CSL Behring Gettin' in the Game℠ Junior National Championship competition in Phoenix, AZ and took 1st place. This was my third year attending the JNC tournament. The first year, I won the Most Improved and Most Enthusiastic award. They added on the Most Enthusiastic part just for me because I hit a great shot and got pretty excited! The second time I went I won 2nd place. Believe me, though, I haven't always been a good golfer. The first time I ever played I hit myself in the head with the club and ended up at the hospital!

I've learned so much by attending; not just about golf, but about things that are even more important, like good sportsmanship, playing by the rules, hard work, leadership, and friendship. I have learned that even though I have Hemophilia, I can be competitive and play sports safely. I am really lucky that my local Chapter provided me with this opportunity, along with CSL Behring. And, because I won, the Western Pennsylvania Chapter of the National Hemophilia Foundation will get $2,500 for education or camp! How cool is that?! I am able to help them and then they can help other families. For taking first place, I also won a trophy (that is almost as tall as I am), a new golf bag, and $500 in new sports equipment. It is something that I will never forget.

Meeting Perry Parker has really made a difference for me. Not only has he helped me with my golf game, but also to see how awesome it is to just help others excel. My goal is to continue attending the event, even if I don't win again, so that I can help mentor the other kids who come to the tournament.

New Mission...New Vision...Your Chapter

One of the most important things any organization needs to do is stay relevant to its stakeholders (in our case, members, the medical community, industry partners, etc.). In this ever changing environment – be it advances in treatment, changes in classification of diagnoses, or healthcare reform – the Chapter strives to continue to meet the needs of the bleeding disorder community in Western Pennsylvania. Over the past two years, the staff and Board at the Chapter have worked diligently to increase the educational offerings, awareness campaigns with state and local elected officials, and support services to our members and will continue to do so. That said, our work does not end there… over the past few months, the WPCNHF Board of Directors has been working on identifying WHAT the Chapter should be doing and WHERE the Chapter should be doing it. Using data from the member needs assessment and various other sources, the Board developed and approved a new mission statement; a vision statement; and a set of core values that we feel, based on the data collected, reflect not only the Chapter, but the entire community.

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.

This new mission statement emphasizes the changing nature of the bleeding disorders community. New treatment options, cures for Hepatitis C, health insurance (and related challenges), prescription drug options and issues have changed how we live our lives and, therefore changed the services that are needed by the membership from the Chapter. All these issues impact our day to day lives so they are important issues to address, be it through education of our members, awareness visits with elected officials, or keeping medical professionals abreast of those issues that affect our community. We need to help members realize that there are so many options out there for them and the Chapter is here help – be it through the Chapter scholarship, patient assistance grants, or education sessions on a myriad of topics. The Chapter is here to help each and every one of you. We strive daily to meet the vast array of needs of this very diverse community.

Our Vision:
To heighten awareness and respect for bleeding disorders while enhancing the Chapter's value and promote and increase members' impact on the broader community.

WPCNHF's new vision extends beyond the immediate community. The Chapter needs to educate people outside the community, both within and outside the world of medical professionals. 1 in every 50 people has a bleeding disorder but 75% of these effected don't know it. We need to increase awareness of bleeding disorders with the medical community to help improve identification and diagnosis. We need to increase awareness among our elected officials at the local, state, and federal level to ensure that well-intended legislation does not unintentionally cause a negative impact on our community. Finally, we need to increase awareness among the public-at-large to allow for our members to continue to be accepted as valued members of the broader community.

We Value:
- Education
- Awareness
- Advocacy
- Empowerment
- Support

These core values are at the heart of everything the Chapter does. These core values drive what the Chapter does each and every day. These values will be used in decision making by the Board and staff in making every decision related to chapter operation and strategy.

With the Chapter's new mission and vision comes an aggressive strategic plan. The Board has given the Chapter Staff very specific goals to achieve in the coming years, ranging from the number and type of educational programs that need to be held to the number of nurses who attend education sessions to learn more about bleeding disorders. We have also tasked the Chapter Staff with diversifying the Chapter's funding stream, including specific attendee goals of people outside the community at fundraising events – which will also serve to increase awareness. We have also tasked ourselves with diversifying the Board composition to enhance our value, as a Board, to the membership.

The primary goals under the Chapter's new strategic plan are as follows:

1. Increase financial stability through a diverse funding stream evidencing the commitment of the membership and the broader community.

(Continued on page 9)

Calendar of Upcoming Events

Thursday, January 29
Advocacy 101
Pittsburgh, PA

Saturday, February 7
Scholarships
Cranberry Township, PA

Wednesday, February 25 - Friday, February 27
Washington Days
Washington, D.C.

Saturday, February 28
Program for Hemophilia Carriers
Homestead, PA

Saturday, March 14
Infusion Day
Cranberry Township, PA

Friday, March 20 - Sunday, March 25
Teen & Parent Retreat
Mars, PA

Monday, April 20
State Advocacy Day
Harrisburg, PA

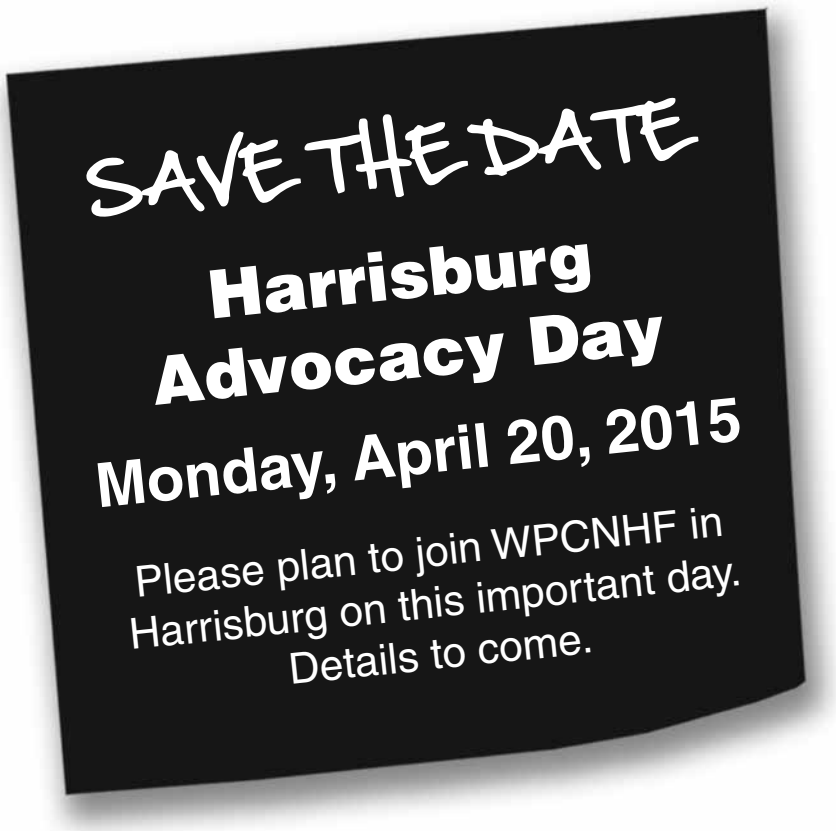
Sunday, June 7 - Saturday, June 13
Camp Hot-to-Clot
Fombell, PA

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!

Winterfest 2014

The Chapter's annual Winterfest celebration took place on December 6 at Dave & Buster's and over 70 people joined in the fun! There were two delicious buffets and games for everyone! This was the final Chapter event for 2014.

We are busy planning events for 2015 and hope to see you soon. As always, if you'd like us to offer a specific program in your area, please let us know. Call the Chapter office at 724-741-6160 or send an e-mail to janet@westpennhemophilia.org.

FDA Approves Oral HCV Combination Therapy Free of Ribavirin and Interferon

On November 5, 2014, the US Food and Drug Administration (FDA) approved the combination use of two previously approved separate oral therapies, Simeprevir (Olysio™) and sofosbuvir (Sovaldi™), for the treatment of chronic hepatitis C viral (HCV) infection. It is a ribavirin- and interferon-free regimen, both of which were notorious for causing debilitating side effects.

Simeprevir, manufactured by Janssen Therapeutics, is a protease inhibitor that halts the progression of HCV, thus preventing it from reproducing. Sofosbuvir, manufactured by Gilead Sciences, is a daily oral nucleotide analogue inhibitor composed of a small molecule compound that blocks HCV's ability to replicate. The FDA approval encompasses the combination use of simeprevir/sofosbuvir for both treatment-naive and treatment-experienced patients. Trial regimens included a 24-week duration for patients with cirrhosis (scarring of the liver) and 12 weeks for those without cirrhosis, both of which excluded the use of either ribavirin or interferon.

The new FDA approval is based on results of the COSMOS study, a phase II trial that included patients with HCV genotype 1. Rates of sustained virologic response (SVR, meaning they no longer had detectable virus in their blood) measured 12 weeks after treatment ended were 93% among those treated with the combination for 12 weeks, and 97% among those treated for 24 weeks. The most common adverse reactions reported by more than 10% of treated patients during 12 weeks of combination treatment were fatigue in 25%, headache (21%), nausea (21%), insomnia (14%), itching (11%), rash (11%), and sensitivity to light (7%). Dizziness (16%) and diarrhea (16%) were the most commonly reported among those patients treated for 24 weeks.

Source: Family Practice News, November 6, 2014.

Gene Therapy Study Still Succeeding Three Years Later

It has now been three years since a group of patients with severe hemophilia B, or factor IX (FIX) deficiency, in London received a single dose of gene therapy as part of a new clinical trial. Early results of the trial were positive as these patients began to generate FIX levels ranging from 1%-6%. Prior to the study, they produced little to none of the crucial clotting factor protein. This seemingly modest boost in FIX "expression" is important. The increase in FIX essentially transforms a patient symptomatically, from severe to mild, with the end result a significant, even dramatic, reduction in bleeds. Results described in a new article indicate that the initial breakthrough results have been sustained during the three years since the study began in 2011.

The report, "Long-Term Safety and Efficacy of Factor IX Gene Therapy in Hemophilia B," was published in the November 20, 2014, issue of *The New England Journal of Medicine*. The lead author of the update was Andrew Davidoff, MD, St. Jude Children's Research Hospital in Memphis, TN. Davidoff has collaborated for more than a decade with a strong team of researchers, including coauthor Amit Nathwani, MD, PhD, at the University College London. "I believe that, scientifically, this is ready for prime time," said Davidoff.

The gene therapy trial employed an adeno-associated virus serotype 8 (AAV8), a small virus that does not cause disease and produces mild immune responses, as a vector (delivery vehicles) to introduce a functioning FIX gene into the liver cells of subjects with severe hemophilia B. The goal of the trial was to trigger viable, long-term FIX protein production through a single administration of the therapy.

Overall, 10 subjects with severe hemophilia B participated in the study, six of whom received high doses of AAV8 and reached average FIX levels of 5.1%. According to investigators, this "resulted in a reduction of more than 90% in both bleeding episodes and the use of prophylactic factor IX concentrate." Also, no toxic effects were reported.

"I think it's going to have a big impact. The study showed both safety and efficacy, and the side effects were minimal," said Timothy Nichols, MD, who heads the Francis Owen Blood Research Laboratory at the University of North Carolina at Chapel Hill. He was not involved in the study. "This is a single shot of medicine given to patients who are treating themselves two or three times a week," he told Reuters Health over the phone. "Suddenly, they don't have to take the medicine anymore."

Source: Reuters, November 19, 2014

THE STORY of our commitment continues WITH A NEW NAME.

With over 60 years of commitment to supporting the bleeding conditions community, we've seen thousands of success stories. This commitment and our passion for innovation will continue with our new identity.

WE PARTNER WITH YOU ON YOUR LIFE'S JOURNEY

Our bold vision for the future of bleeding conditions–"Pursuing a life without bleeds, one person at a time"–can be seen in everything we do:

- Leading investments in research
- Offering a vast array of programs and support
- Employing a staff who is dedicated to serving you every day

Our proven past, the advancements we're making today, and our passion for the future fuel our promise: **Our relentless pursuit continues until a life without bleeds is a reality for all.** This is what makes us the company we are. Even though we will have a new name, our pursuit will continue on.

Learn more about Baxter resources and support at nava.baxter.com

Baxter

NHF 2014 Reflections

By Patrick McFarland

This summer I had the opportunity to go to the NHF conference in Washington, D.C. It was my first time attending an NHF conference and, wow, it was amazing. I was blown away by the huge variety of things to do and places to visit. My wife and I hardly had a chance to do some sightseeing because nearly every day was packed full of sessions, dinners, and visits to vendor booths!

Speaking of vendor booths, the exhibit hall was beyond belief. Before going to the conference, I had received several brochures in the mail from many of the companies, so I thought I had an idea of what to expect. But I was sorely mistaken. Sitting in a space the size of two football fields was booth after booth and much, much more than tables with a few brochures and posters. Many of the vendor displays were huge undertakings including studio lighting, sounds systems, science experiments, and even ice cream! One vendor turned their whole area into a game show complete with a host who walked around talking to all of the contestants.

While it was nice to check out all the cool booths and what they had on display (not to mention the swag!), it was really about making connections with vendors and suppliers. I had a chance to put names to faces and get to know who is working behind the scenes to provide the medication and supplies I need. I'm now 100% confident that if I ever have an issue, at any level, I know who I would need to speak with to get it sorted out. I also found out about a few men's groups that I had never heard of that I'd love to get involved with.

Then, of course, there were all the sessions. Not only did they feed us delicious meals for breakfast, lunch, and dinner nearly every day, but there was information about every facet of hemophilia. There were sessions about longer lasting prophylactic treatment. There was a series on fitness with great information about exercises and how to keep track of your progress. There were also several sessions just for women with all sorts of information that neither of us had a chance to attend, but heard were great. There were sessions for financial planning which, while not what I had expected, were an eye opening look at the future and some steps that I could put in place now to make huge difference.

All of this tied together with chances to mingle with other hemophiliacs and make friendships that will last a lifetime. I moved around a lot while growing up and didn't have much of a chance to get involved with the hemophilia community, but now I've had a chance to see what I've been missing. I may not have been able to go to camp or do a 5k run, but I'm glad that I'm getting involved now. Talking with some of the older hemophiliacs, I have come to realize just how far we've come, even in just my lifetime. It gives me great hope for the future; the only thing standing in our way is public understanding and funding. With the progress that is being made with the human genome, it's finally not an issue of if a cure will be found, but when.

I'm so thankful of the NHF and the various sponsors for organizing the events that enabled all of us to meet up, exchange information and experiences, and then return to our local chapters to spread the word and hope for the future.

Our First Trip to a National Hemophilia Foundation Conference

By Delores Johnson

I remember feeling a thousand different emotions when hearing that my son and I would be attending a conference in Washington D. C. I have wanted to go for years and it never seemed to work out. I started talking with people who were attending so I knew who from our hemophilia support team would be there for us, in a time of need. The conference was so different than I imagined. I didn't imagine having to choose one educational seminar over another or having to divide two meetings in half, so I could learn from both sessions.

We rode the bus from Pittsburgh to D.C. The ride in was amazing. I had not been to D.C. since college, back in 1998. We came in through the city and were able to see all the important monuments, as we headed to Union Station to take the subway to the hotel. My son, Ethan, was super excited to see the sights. But once we checked into the hotel, the only thing that mattered was the pool which was still open in the middle of September and still warm enough to swim in! We did have an agenda to follow, however, so pool time was limited for him.

Arriving at the Marriott was overwhelming in a sense. As I was walking the long halls and passing the presidential rooms, I began to feel this was all much too big for little old me, but I found the registration booth and registered myself and Ethan with no problems. My son was instantly attracted to the art exhibit by FLOX, which celebrated creative individuals from the bleeding disorders community with

their original works of art and music. He was stuck on the music and we sat for

an hour as he listened. People you may have never met before cared to hear your story and they offered advice, if you needed it. I even found opportunities to share some advice with others. We always had somewhere to be and it was nice to feel wanted.

We had to maintain a school schedule, so Ethan still had to get up early in the mornings to get to the kids' program. There were many activities for the kids, which gave parents the freedom to attend the daily sessions taking place all over the hotel. Freebies were everywhere (next time I know to take an empty suitcase for them, LOL)! I met many Facebook friends in real life, which was very nice. I also met many new people from our Chapter who helped me when I needed it the most. They helped me find supplies for a nose bleed Ethan had after swimming in the pool. In addition, my son hurt his ankle and although I packed extra factor, I didn't pack enough extra supplies, so a generous family gave me a syringe. Another family got ice for us while I was in the room, unable to leave my son alone. I am grateful to all of them.

The trip to the National Zoo was fun and I really enjoyed the National Air and Space Museum. The planes at the museum were amazing—I have always loved the old war planes. While at the museum, I met Rich from HFA; he asked to take my picture because I was wearing my "I love someone with Hemophilia" shirt. I was honored to learn that he helped design the shirts.

I didn't think I could learn so much in such a short time, but I did and I am grateful for the opportunities I received from the Chapter and NHF. THANK YOU ALL FOR A WONDERFUL EXPERIENCE!!!

Oktoberfest

Go to Dinner, Go to Jail?? That was the attention-grabbing title of the presentation given by Dawn Rotellini, Vice President Chapter Development & Education, National Hemophilia Foundation, at the Chapter's Oktoberfest! This program was packed with information about terms and organizations affiliated with the bleeding disorders community. Dawn defined acronyms that can sometimes cause confusion and also talked about the relationships and rules involving chapters, patients/members, pharmaceutical companies, and home healthcare companies.

One of the recommendations from NHF, when choosing a home healthcare provider, is to ask potential providers and your insurance company a series of questions. Compare prices and services to help ensure that you are receiving the best possible care. Keep in mind that your insurance company might dictate which providers you can choose from, so be sure to contact your insurance company before contacting home healthcare providers.

The following is a recommended list of questions for home healthcare providers:

- Are you a preferred provider under my insurance plan?
- What is your policy on co-pay and deductible costs? Do you have a financial assistance plan?
- What are your hours of operation? Do you have a toll-free customer service line that is available 24 hours a day?
- What is the standard delivery time (24 hours, 48 hours, etc.)?
- What is your policy on emergency orders?
- Do you have an emergency plan in place in the event of a natural disaster or other emergency?
- Do you have an adequate supply of the factor I need on hand and in the right assay size?
- Are all of the ancillary supplies included with my order?
- What is the cost per unit for my clotting factor?
- What additional ancillary services do you provide (nursing, physical therapy, etc.)? What is the cost for these services?
- Will I receive copies of all billing invoices?
- Do you participate in the Patient Notification System for clotting factor recalls?

HAPPY NEW YEAR

Thank you for allowing us to serve
You during 2014
Wishing you a happy and healthy
New Year for 2015!

From the staff at the Hemophilia Center
of Western Pennsylvania

Spotlight on the Member: Andrew Kotuce

Life with Hemophilia is a life of balance. Finding ways to stay active and involved without putting your health at risk can sometimes feel like walking a thin tight-rope. However, a long time ago I stopped asking the question, "*Can* I do this?" and started asking the question, "*How* will I do this?"

My name is Andrew Kotuce, I'm a 25-year-old Pittsburgh native and live with my wonderful girlfriend and our new puppy in a town right outside of downtown. I work for Verizon Fios as a Fiber Customer Support Analyst (fancy name for technical support) and am studying for my bachelor's degree in Information Technology. I have come far in my life and couldn't be happier than I am at this moment – but it was a long and arduous journey.

I was diagnosed shortly after birth with severe Hemophilia A and immediately began a life filled with routine infusions and what I originally viewed as "limitations." Being energetic and active (as many little boys are) I found it endlessly frustrating that I was constantly told no. "No, you can't participate in gym." "No, you can't go play roller hockey." It was as if they were telling me, "No, you can't have a life." It wasn't until I started attending Camp Hot-to-Clot that I finally heard "yes." It was as if an entirely new world was opened up to me. It was there that I learned to push my boundaries without overstepping them and how to properly care for myself to become independent. It was as if the blinders were removed and I was seeing the world from a new viewpoint for the first time. My diagnosis no longer defined my life and it was liberating to know that a world of possibilities and "yeses" lay ahead of me.

This experience was so transformative for me that I felt it necessary to share this wonderful new concept with other struggling children. When I became old enough, I became a camp counselor at Camp Hot-to-Clot so that I could share this with the next generation of children living with hemophilia. Being a camp counselor was and is one of the most rewarding experiences of my life and I feel blessed to have had the incredible opportunity to change these children's lives in some way. Of the countless campers I've worked with, if even one of them changed the way I did, then all of the hard work was more than worthwhile.

Now that I've become an adult, working on advancing my career, and creating a family of my own, it's become increasingly difficult to work as a counselor. But even spending a few days as a volunteer is rewarding – never mind a complete blast. The men and women in the WPCNHF have truly become my family and spending that time with them is like visiting home. Maybe even a little more fun.

Whenever I meet new parents in the bleeder community (as we lovingly call ourselves), I tell each one of them the same thing: "Don't limit your child." This almost always scares them as, of course, the initial instinct is to protect

their child from anything and everything at all costs. Of course it is critically important to take those extra measures for safety when you're a bleeder. Life must be about balance. It's about being prepared for emergency situations and taking proactive steps to reduce the risk of injury, but it's also about living your life to the absolute fullest and coming out from that shadow of fear.

I love my life and everything in it, and I outright refuse to let my disorder dictate what I can and can't do. For those of you out there who are struggling, don't be afraid to reach out. The WPCNHF and the Hemophilia Center of Western PA are incredible resources, specifically founded to help people like you—people like me. I owe a great deal to these organizations for the work they have done to educate, medicate, and assist me in virtually every aspect of my life. Stay smart, stay strong and make every day count!

New Mission... New Vision... Your Chapter

(Continued from page 2)

2. The membership shall be empowered to speak out for their own needs and shall contribute to the broader community within their means beyond that of the bleeding disorders community.
3. Increase awareness of bleeding disorders to the broader healthcare and non-healthcare community through educational and outreach efforts.
4. Recruit and retain a diverse board committed to moving the chapter forward with resolve and determination.

The Board realizes these are lofty goals – and it has outlined very specific initiatives for the Chapter Staff (and the Board itself) to work toward these goals. Over the coming years, we hope that the result of this new strategic plan will be that you will find a Chapter that is stronger, more able to provide you with the services you need, and more relevant to your current needs in this new world.

Half the volume
Twice the factor*

ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is now available in a **2000 IU FVIII vial** with a reconstitution volume of only **10 mL**.

*That's **TWICE** the amount of factor of the largest vial available for other FVIII/VWF products,[1-4] so patients may require:

- **Less volume**
- **Less time**
- **Fewer syringes**

Isn't it time you tried ALPHANATE?

Learn more at **alphanate.com**

Alphanate®
Antihemophilic Factor/von Willebrand Factor Complex (Human)

Indications

ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is indicated for:

- Control and prevention of bleeding in patients with hemophilia A
- Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand disease (VWD) in whom desmopressin (DDAVP®) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery

Important Safety Information

ALPHANATE is contraindicated in patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with ALPHANATE should be discontinued, and emergency treatment should be sought.

Development of activity-neutralizing antibodies has been detected in patients receiving FVIII containing products. Development of alloantibodies to VWF in Type 3 von Willebrand disease (VWD) patients has been occasionally reported in the literature.

Thromboembolic events may be associated with AHF/VWF Complex (Human) in VWD patients, especially in the setting of known risk factors.

Intravascular hemolysis may be associated with infusion of massive doses of AHF/VWF Complex (Human).

Rapid administration of a FVIII concentrate may result in vasomotor reactions.

Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

The most frequent adverse events reported with ALPHANATE in >5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain, and fatigue.

Please see brief summary of ALPHANATE full Prescribing Information on adjacent page.

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

References: 1. ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) Prescribing Information. Grifols. **2.** CSL Behring. Humate P Package Insert. August 2013; **3.** Octapharma. Wilate Package Insert. January 2012; **4.** Kedrion. Koate-DVI Package Insert. August 2012.

For more information: **Grifols Biologicals Inc.**
Tel. 888-GRIFOLS (888-474-3657)

Grifols Biologicals Inc.
5555 Valley Boulevard, Los Angeles, 90032 CA - USA Tel. 888-GRIFOLS (888 474 3657)
www.grifols.com

GRIFOLS

ALPHANATE®

Antihemophilic Factor/von Willebrand Factor Complex (Human)

HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use Alphanate safely and effectively. See full prescribing information for Alphanate.

ALPHANATE (ANTIHEMOPHILIC FACTOR/VON WILLEBRAND FACTOR COMPLEX [HUMAN])

Sterile, lyophilized powder for injection.

Initial U.S. Approval: 1978

----------INDICATIONS AND USAGE ----------

Alphanate is an Antihemophilic Factor/von Willebrand Factor Complex (Human) indicated for:

- Control and prevention of bleeding in patients with hemophilia A.
- Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand Disease in whom desmopressin (DDAVP) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery.

----------DOSAGE AND ADMINISTRATION ----------

For Intravenous use only.

Alphanate contains the labeled amount of Factor VIII expressed in International Units (IU) FVIII/vial and von Willebrand Factor:Ristocetin Cofactor activity in IU VWF:RCo/vial.

Hemophilia A: Control and prevention of bleeding episodes

- Dose (units) = body weight (kg) x desired FVIII rise (IU/dL or % of normal) x 0.5 (IU/kg per IU/dL).
- Frequency of intravenous injection of the reconstituted product is determined by the type of bleeding episode and the recommendation of the treating physician.

von Willebrand Disease: Surgical and/or invasive procedure in adult and pediatric patients except Type 3 undergoing major surgery

- Adults: Pre-operative dose of 60 IU VWF:RCo/kg body weight; subsequent doses of 40-60 IU VWF:RCo/kg body weight at 8-12 hour intervals post-operative as clinically needed.
- Pediatric: Pre-operative dose of 75 IU VWF:RCo/kg body weight; subsequent doses of 50-75 IU VWF:RCo/kg body weight at 8-12 hour intervals post-operative as clinically needed.

----------DOSAGE FORMS AND STRENGTHS ----------

- Alphanate is a sterile, lyophilized powder for intravenous injection after reconstitution, available as 250, 500, 1000, 1500 and 2000 IU FVIII in single dose vials.

----------CONTRAINDICATIONS ----------

- Patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

----------WARNINGS AND PRECAUTIONS ----------

- Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with Alphanate should be discontinued, and emergency treatment should be sought.
- Development of activity-neutralizing antibodies has been detected in patients receiving FVIII containing products. Development of alloantibodies to VWF in Type 3 VWD patients has been occasionally reported in the literature.
- Thromboembolic events may be associated with AHF/VWF Complex (Human) in VWD patients, especially in the setting of known risk factors.
- Intravascular hemolysis may be associated with infusion of massive doses of AHF/VWF Complex (Human).
- Rapid administration of a FVIII concentrate may result in vasomotor reactions.
- Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

----------ADVERSE REACTIONS----------

The most frequent adverse events reported with Alphanate in > 5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain and fatigue.

To report SUSPECTED ADVERSE REACTIONS, contact Grifols Biologicals Inc. at 1-888-GRIFOLS (1-888-474-3657) or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

----------USE IN SPECIFIC POPULATIONS ----------

- Pregnancy: No human or animal data. Use only if clearly needed.
- Pediatric Use: Hemophilia A - Clinical trials for safety and effectiveness have not been conducted. VWD - Age had no effect on PK.

GRIFOLS

Grifols Biologicals Inc.
5555 Valley Boulevard
Los Angeles, CA 90032, U.S.A.
U.S. License No. 1694

3041048-BS
Revised: 06/2014

Yard Workout: Shaping up without leaving home

By Matt McMillen | 11.17.2014

Article courtesy of HemAware copyright 2014

Your next workout is waiting just outside your door. Grab a rake, a push lawn mower and some gardening tools, and get fit in your yard. While you shape up your property, your yard work will help get you in shape, too. "Raking gives you a great upper-body workout, and that's something a lot of people don't get," says physical therapist Grace Hernandez, PT, of the Children's Hospital of Orange County Hemophilia Program in Orange, California.

Raking leaves, pushing a lawn mower, clipping your hedges, weeding your garden and other outdoor chores not only make you stronger, they'll slim you down as well. A 155-pound person burns nearly 300 calories for every hour spent raking. Using a manual mower, the same person will zap close to 400 calories in 60 minutes. Gardening can be nearly as vigorous, according to stats from the Wisconsin Department of Health and Family Services. "It's a real workout," says Hernandez.

However, yard work should be a part of an overall exercise routine. "You shouldn't rely on yard work as your sole form of exercise, but it certainly would make a nice supplement to exercises you already do," says Luke Smith, PT, DPT, CEAS, CSCS, a physical therapist at Thomas Jefferson University Hospital in Philadelphia.

Body mechanics

Anyone new to exercise and to yard work should see a physical therapist (PT) before getting started. Your PT will help you learn safe ways to perform each of the tasks you want to accomplish.

"Good body mechanics are crucial," says Hernandez. "If you have an elbow problem, for example, your therapist could show you a better way to lift and carry things so that you use more of your shoulder, back and leg muscles," she says. Proper mechanics decrease stress on joints, she adds.

How much you carry is just as important as how you carry it. "Instead of carrying big bags of sod, separate them into smaller loads," Hernandez says. Make multiple trips with your wheelbarrow, so all the weight isn't in one load. She recommends garden wagons for hauling heavy loads and roller stands for cumbersome plants.

When you're working in the yard, try to keep a neutral body position, says Smith. That means your ears should be above your shoulders, which should align with your hips. "You want to minimize the bending and twisting as much as you can," he says. "This is especially important for people with more severe forms of hemophilia who need to be extra cautious about joint strain."

Another tip: Treat your rake as a dance partner, Smith says. Hold it as close to your body as possible when you work. Rather than stretching out to drag leaves to you, step toward the leaves so that you don't have to reach very far.

Also, avoid kneeling in the dirt, Smith cautions. Instead, consider purchasing a gardening bench. It will allow you to get close to the earth without straining your knees.

Taking precautions

Yard work will make you sweat, so keep water handy to stay hydrated. Protect yourself from the sun by wearing a hat with a wide brim and slather on the sunscreen. Gardening gloves sized to fit your hands can help prevent blisters from using a rake, manual mower and other tools.

Don't try to do too much at once, though. "Listen to what your body is telling you," says Smith. You can avoid injury if you work on one task for a short while, then take a break or switch to something different. This is especially important if you have a problem joint. If you have a bad shoulder, rake only a few minutes at a time before resting for a bit, says Smith.

To get the most out of your yard work workout, use manual tools. The extra effort they require will burn more calories and help you build more muscle. But electric tools still provide benefits. "Even if you use electric leaf blowers or clippers or mowers, you can still burn calories just by holding and moving those power tools," says Hernandez. "You can get fit just working in the yard."

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

Board of Directors

President
Scott Miller, CPA, Esq.

Vice President
Nathan Rost

Treasurer
Sam Rotellini

Secretary
Mike Covert

Director
Nick Vizzoca

Directors Emeriti
Jim Loll

Missy Unkovic

Staff

Executive Director
Alison Yazer

Member Services Manager
Janet Barone

Bookkeeper & Office Assistant
Kara Dornish

Fundraising & Events Manager
Brittani Reed

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:

The Western Pennsylvania Chapter of the National Hemophilia Foundation is leading the way in Western Pennsylvania in improving the quality of care and enriching the lives of those with bleeding disorders through education, advocacy, resource, and referral.

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@westpennhemophilia.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
- Apartment-sized refrigerator

5th ANNUAL TAKE A BOUGH
HOLIDAY TREE AUCTION TO BENEFIT WPCNHF

The 5th Annual Take A Bough was held at One Oxford Centre, November 19th-22nd. It was an exciting year for the Chapter, as we raised over $60,000! We are extremely grateful for the donations we received from our Chapter members, our partner organizations, and other donors who offered their support. The new location enabled WPCNHF to increase awareness not only of the event, but of the Chapter and bleeding disorders in general. This year, a number of items were won by people outside the community, which demonstrates the successful increase in awareness!

Planning and preparation for the 5th Take A Bough began months prior to the event! We could not have done it without the hard work and dedication of our volunteer planning committee. Special thanks to the following committee members: Anne Graham, Melissa Kendrick, Nora Latcovich, Dawn Rotellini, Diane Standish, Maria Steele Voms Stein, and Laureen Temple.

Between November 13th and November 17th, volunteers helped transform an unoccupied retail space into a holiday extravaganza by setting up over 85 trees, wreaths and tabletop displays donated by individuals and businesses from all over Western Pennsylvania. A huge thank you to Two Men & A Truck for helping us move in and out of the space and also to Highmark Healthcare and Cigna Healthcare for sending volunteers to help unpack and set up the space! We'd also like to thank Oxford Development for donating the display space and The Rivers Club for hosting our final reception.

The event ended with a lovely Sponsors & Patrons Reception on November 23 at The Rivers Club. Christmas music was sung by the talented Nina Sainato. Brittani Reed thanked all the sponsors and Alison Yazer spoke about the exciting year the Chapter had and then sadly, wished Brittani well as she moves on to a new position at the University of Pittsburgh Medical & Health Sciences Foundation.

Successful fundraisers like Take A Bough allow the Chapter to continue improving the quality of care and enriching the lives of those with bleeding disorders in Western Pennsylvania. WPCNHF would like to thank all who sponsored the event, donated items and to all who volunteered their time to help make the event such a resounding success!

WPCNHF Winning Women and Teen Volunteers

We thank both the women of the Chapter and the young members who donated their time to help the Chapter prepare for the Take A Bough fundraiser!

The teenagers joined us on Saturday, November 15 and decorated the "Camp Hot-to-Clot" trees with decorations that kids created during summer camp. After they finished decorating the trees, Tori Baker, a student at Slippery Rock University, talked with the teens about opportunities in the bleeding disorders community and how she has personally benefitted from them. Before parting, the group also talked about ideas for upcoming teen programs and social events. A survey will be conducted in the near future to help determine interests and best dates in 2015 for teens of the Chapter. If you are not currently receiving e-mails from the Chapter and would like to be included in the survey, please contact Janet Barone at 724-741-6160 or send an e-mail to rsvp@westpennhemophilia.org.







BAYER HEALTHCARE AND THE HEMOPHILIA COMMUNITY

commitment, leadership & innovation

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

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

WPCNHF