

NHF/DVC

The Winning Spirit

Quarterly Newsletter
National Hemophilia Foundation
Delaware Valley Chapter
Winter 2011 - Volume 18 #1

How the New Healthcare Law Can Help You

By David Linney

Much of the federal healthcare reform that passed in March 2010 will not take effect until 2014. However, key parts of the legislation began this fall, offering expanded insurance benefits and protections to members of the bleeding disorders community now and during the next year.

End of Lifetime Limits

Beginning September 23, 2010, as individual and group health plan policies are issued or renewed during the next year, they will no longer have lifetime limits. By September 22, 2011, no health plan will have a lifetime limit.

Annual Limit Minimums

Until January 1, 2014, when annual limits for all insurance plans will be abolished, the law sets a minimum annual limit dollar amount for all group policies and new individual policies. (However, the law does not apply to existing individual policies.) For a plan or policy year beginning between September 23, 2010 and September 22, 2011, the minimum annual limit can be no less than \$750,000. That amount will increase in subsequent years.

Addressing Pre-Existing Condition Exclusions

Individual and group health plan policies issued or renewed on or after September 23, 2010, will no longer be permitted to exclude or restrict coverage for an individual younger than age 19 with a pre-existing condition. By September 22, 2011, no policy will be able to exclude this group.

End of Insurance Plan Cancellations

As of September 23, 2010, individual and group health plans cannot cancel an insurance policy because an individual had high-cost medical claims.

Medicare Drug Benefit Savings

This year, Medicare will provide a one-time \$250 rebate to help pay for prescriptions in the "donut hole," a gap in Medicare part D coverage that occurs when drug costs exceed the initial coverage limit, but do not reach the catastrophic coverage threshold.

In 2011, there will be a 50% discount on covered brand-name prescription drugs for those in the donut hole.

Coverage for Children

All children younger than 19, regardless of medical condition, must be accepted by individual plans for an individual policy (for the child) or as a dependent under an approved family policy.

New Dependent Coverage Limit

The law requires all insurance plans that offer dependent coverage under a parent's policy to provide it until an adult child turns 26, whether single or married. The only exception is if the parent has an employer-based plan and the child is eligible for his or her own employer-based coverage. By September 22, 2011, all eligible adult children should be enrolled.

New Pre-Existing Condition Insurance Plans

If you have a pre-existing condition

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PSI

If you need help paying insurance costs, go to our website for more information or call 800-366-7741

www.hemophiliasupport.org/fyi.htm



www.hemophiliasupport.org

FROM THE EXECUTIVE DIRECTOR

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Graphic Artist: www.chaley.com

We gratefully acknowledge the pledge of support from the following manufacturers for 2011.

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DVC Welcomes a New President



Keith Moore, Past President of the Delaware Valley Chapter was recently elected to the National Hemophilia Foundation's Board of Directors. "As President of the DVC for four years, Keith made many substantial improvements in Chapter operations, including the development of a Strategic Plan and improvements in policies and guidelines for increasing our service to local families affected by bleeding disorders," said Andy Serrill, Treasurer. "We know Keith will continue his leadership on a national level by serving on the NHF board." Keith will remain an active member of the DVC.



Tom Galvin, Past Vice President of the DVC, has assumed his new role as President of the Chapter. Tom is very capable to lead our organization. His strong business skills and compassionate heart are just the right mix to continue the advancement of our goals to support patients and families. We wish Keith all the best and welcome Tom to his new role!

Delaware Valley Chapter members continue to send in generous contributions for the NHF's Phase II, Campaign for Our Future. Funds collected for this important appeal are applied directly in support of important research bringing the promise of a cure closer than ever before. We hope that each of our readers will participate in the best way they can. Every dollar counts!

James R. Lindquist



A very strong advocate for people with bleeding disorders and Past Vice President of the Delaware Valley Chapter board died on November 24, 2010. Jim served the Chapter in many capacities, spanning almost twenty years. Jim co-chaired the Annual Fall Gala, with his wife Lynn and served as a board member and Vice President over the last 15 years. As a Principal and Director of Electrical Services at Kling-Stubbins of Philadelphia, Jim used his business skills and talents to effect significant improvements in the Chapter's operations, including technical planning and upgrades to the Chapter's technology systems and the design of our Annual Report and Membership Appeal. Jim was an idea person with a compassionate heart. He committed a significant amount of time helping the Chapter be a stronger organization. He was recognized not only as a leader, but as a sensitive and kind man who focused on trying to help our community in countless ways. Over the years, Jim was recognized by both the Delaware Valley Chapter and the National Hemophilia Foundation for his volunteer leadership and commitment to improving the lives of people affected by hemophilia and von Willebrand Disease. He was a shining example of what the word "advocate" truly means. Jim will live on in our memories and in our hearts. He is missed already.



Winning Spirit Newsletter GOING GREEN!!!

If you would like to receive your quarterly Winning Spirit via email (rather than through the mail), contact the Delaware Valley Chapter (hemophilia@navpoint.com) and let us know. Provide the following information in your email:

Name
Current mailing address
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Beginning with the winter newsletter edition (2011), you will begin to receive your newsletter via your email. NOTE: IF YOU ARE A PATIENT REGISTERED AT AN AREA HTC, YOU WILL CONTINUE TO RECEIVE A HARD COPY VIA YOUR TREATMENT CENTER.



CHAPTER HAPPENINGS

Here's what's been happening!!



Roaring 20's Fall Gala, Friday, October 22, 2010!

A beautiful night for the Chapter which raised more than \$100,000 to support our mission of service. We thank Pfizer, event sponsor and Megan and John McEnroe and their wonderful committee that made this a special night to remember!!



I Can Run 5K and Hemophilia Walk, Saturday, October 2, 2010!

More than 650 runners and walkers participated in the I Can Run 5K and Hemophilia Walk to benefit the DVC!! What a fantastic day with over 30 teams raising more than \$115,000 to help fund research and programs. Thank you to all the team captains and a special thank you to Heather Thompson, our walk Chairperson, for all her hard work. Don't forget—save the date for the 2011 event: Saturday, October 1, 2011. Teams will be forming in the spring. Call Christine Rowe at the DVC office for more information and how to participate in this event.



NHF Annual Meeting, New Orleans, November 11-13, 2010!

This annual meeting was held in New Orleans, LA and provided a program of education and information to people with bleeding disorders, medical providers and scientists. The DVC was proud to receive a Volunteer Service Award for Pat Felthaus, current DVC board member. Keith Moore, Past DVC President, received a Philanthropist of the Year Award. Both Pat and Keith were acknowledged for their leadership and volunteer service to the Delaware Valley Chapter. Congrats to both!

Annual Holiday Party, Saturday, December 4, 2010!

More than 300 families gathered for this annual event at Jefferson Hospital in Philadelphia. Lots of fun, presents for the kids, wonderful food and arts and crafts made this day a special holiday event!! Pictures with Santa were a big hit!! A big thank you to Kim Bayer and her awesome committee for all their hard work!!



CHAPTER HAPPENINGS

2011 Chapter Calendar

Call the DVC office (215-885-6500) for detailed information about the events listed here.

February

16-18 NHFs Washington Days!

26 Bowling for Fun!

April

9 Annual Fashion Show!

29-5/1 Women's VWD Retreat!

May

3 Annual Family Dinner!

14 Broad Street Re-Run!

June

11 BBQ Cookoff/Grilling for a Cure!

July

7-12 Dragonfly Forest Camp!

18-23 Woods' Camp: Session #1! (not confirmed)

August

3-8 Woods' Camp: Session #2! (not confirmed)

September

19 Annual Golf Classic!
23-25 Annual Family Camp!

October

1 DVC Walk/Run!
8 Couples' Retreat!
21 Fall Gala!

November

10-12 NHF Annual Meeting/Chicago!

December

3 Annual Holiday Party!

Here's what's coming up!!

For detailed information on the following events or to REGISTER, call the DVC office (215-885-6500) or e-mail kimb@hemophiliasupport.org



Bowling for Fun, Saturday, February 26, 2011!

This is the best family event, ever! A fantastic day at Thunderbird Lanes

in Northeast Philadelphia. Bowling, pizza, prizes and more!!

Annual Fashion Show and Luncheon, Saturday, April 9, 2011!

The DVC Ladies' Committee has lots of surprises in store for you! A day of fashion and a special guest will make this the perfect spring event at the Drexelbrook in Drexel Hill, PA!

Women's VWD Retreat on the Hill, April 29-May 1, 2011!

This is a weekend of education and relaxation for women in families affected by VWD. Education and programming are provided by local experts from the Hemophilia Treatment Centers. Will be held at the beautiful ACE Conference Center in Lafayette Hill, PA. This event is made possible by a grant from CSL Behring.



Annual Family Dinner, Tuesday, May 3, 2011!

Join other families at the Annual Family Dinner, held at the Hilton Hotel, City Avenue, Philadelphia. An informative night

that provides updates and a program of interest for local Chapter members. *Together We Can Make a Difference* (our theme for this year) will feature presentations on treatment in other parts of the world for people with bleeding disorders. Don't miss this spectacular evening!



Broad Street ReRun, Saturday, May 14, 2011!

This 5-Mile Run, 1/2-Mile Kids' Run and a 1-Mile Family Walk is in its third year! Join us at the Pavilion Shopping

Center in Lansdale, PA on South Broad Street. Bring the whole family and join Super Mario and Luigi from Nintendo at this fantastic event to benefit the DVC!! Great food and goodie bags to all pre-registered... register now at www.broadstreetrerun.com.



Harry Green, Chair of the Keller Williams Charity Golf Tournament presents check to Christine Rowe, DVC. Thank you Keller Williams for your generosity!

Carlino's Golfing for a Cure, Monday, June 6, 2011!

Sponsored by Carlino's Foods in Ardmore, PA, this is one of the nicest events of the year! This will be held at the Edgemont Country Club in Edgemont, PA. Food, fun, golf. What could be better?



BBQ Cookoff/Grilling for a Cure, Saturday, June 11, 2011!

Two great events in one and both for a great cause! Bring a team to BBQ if you think you are up for

this cooking challenge or sign up as a team to play horseshoes. Games, music, tons of food. To register or find out more, go to: www.bbqcookoff4acure.com.

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and have been without insurance for six months or more and have no insurance options, the law has created a pre-existing condition insurance plan in each state. Often referred to as

temporary high-risk pools, these plans will serve as a bridge until 2014, when all individuals, including those with pre-existing conditions, will be able to purchase qualified individual plan

coverage through state-based American Health Benefit Exchanges.

Previous article taken from the Fall 2010 *HemAware*, a publication of the National Hemophilia Foundation.

Sports and Von Willebrand Disease

Exercise is nothing to fear By Lisette Hilton from HemAware.org 03.24.2010



Having **von Willebrand Disease** (VWD) doesn't hold Ray Pierce back. The 20-year-old junior at Catholic University of America in Washington, DC, swims freestyle sprint and breaststroke for his college swim team. Throughout his life, he has done gymnastics, played baseball (as third baseman and outfielder), run track and played basketball and he continues with his favorite sport, karate.

VWD is a hereditary condition, caused by a defect or deficiency of the von Willebrand factor blood clotting protein. VWD occurs equally frequently in males and females. It is associated with recurrent nosebleeds and heavy periods in women, as well as gastrointestinal traumatic and postoperative bleeding, according to Margaret Ragni, MD, MPH, director of the Hemophilia Center of Western Pennsylvania.

Pierce was diagnosed with Type I VWD at three years old. Although symptoms are typically mild, he bleeds often. He enjoys being active, but having VWD makes Pierce think before he leaps into a new sport. Taking necessary precautions and listening to his body are the name of the game for him. To avoid injury, Pierce focuses on the sports he likes most and makes sure to train specifically for them by using protective gear and doing stretching and strengthening exercises.

Which Sports for You?

People with all types of bleeding disorders—even the most severe types of hemophilia—should get some form of exercise, experts agree. For people with VWD, the health benefits of being

in shape outweigh, in most cases, the risks of playing sports, says Ruth Ann Kirschman, WHNP, BSN, women's health nurse practitioner at the Mountain States Regional Hemophilia and Thrombosis Center, University of Colorado, Aurora. "Muscles that are not in good shape cannot hold the joints in proper alignment and protect them." As active as Pierce has always been, he has not played organized football or hockey.

For people with VWD, these are among the sports that are considered particularly dangerous, says Sherry Herman-Hilker, PT, MS, University of Michigan Hemophilia and Coagulation Disorders Program, Ann Arbor. "We don't encourage high-contact sports because of the risk of abdominal or intracranial [within the cranium] bleeding," Kirschman says. "But we do encourage weight control and muscle training and fitness as a protection against bleeding. We love swimming. It's an excellent sport because it works the opposing muscles adequately, so you get the best balance of muscle toning through swimming without the trauma to the joints that can cause joint bleeding in those with bleeding disorders." "The safe sports are those where the benefit of participating clearly outweighs the risks under all circumstances. In the dangerous sports, the risks outweigh the benefits in most circumstances," Herman-Hilker says.

Other high-risk or dangerous sports include rugby, trampoline jumping and power lifting. Sports that are

generally considered safer include archery, golf, hiking, tennis, rowing and bowling, according to the *Playing It Safe: Bleeding Disorders, Sports and Exercise* booklet published in 2005 by the National Hemophilia Foundation (NHF) and distributed by HANDI, NHF's information resource center.

Soccer falls into the moderate-risk category, says Thomas C. Abshire, MD, Hemophilia of Georgia, Inc., professor of pediatrics and director's chair in hemostasis, Aflac Cancer Center and Blood Disorders Service, Emory University and Children's Healthcare of Atlanta. "Some sports, such as soccer, should be approached with caution, especially when the child begins to head the ball. Most would agree that competitive soccer in the teenage years is a contact sport," Abshire says. "Other sports such as basketball or baseball, where contact with another person or object [ball or stick] may occur, are probably okay for type I VWD, due to the low likelihood of injury. In general, however, it is probably best to have children with VWD become involved with a sport where injury is unlikely, so that they can develop an interest and an expertise early in their school-age years."

Take Precautions

Before beginning a sport, people with VWD should talk with their hematologists and hemophilia treatment center (HTC) physical therapists, according to Angela Forsyth, PT, DPT, a physical therapist at the University of Pennsylvania

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Hemophilia and Thrombosis Program in Philadelphia.

There are three levels of VWD, from Type I on the mild end of the spectrum to the more severe Type III. Patients with a mild condition often have a broader range of sports options, but even they have to take into consideration their individual health concerns. When determining which sports might be best for individual patients, HTC physical therapists often ask VWD patients about their bleeding histories and what causes their bleeds. “If I have a patient with Type III VWD who has recurrent left knee bleeds, then I am not going to recommend that he aggravate the problem with running or basketball,” Herman-Hilker says. “If he, on the other hand, has an elbow problem, then the exercise choices would be different.”

Once people get the OK from their hematologist or HTC and parents to participate in a sport, they should concentrate on preparing for it. “Make sure you know appropriate stretching and warm-up activities before your first practice,” Herman-Hilker says. “I would also make sure that you are communicating with coaches, exercise instructors and others so that these folks understand your condition, the risks and how to assist you if you should have a problem.” For people who have more severe types of VWD, prophylaxis might be necessary to achieve necessary factor levels prior to higher-impact or higher-exertion sports. Girls and women with heavy menstrual flows sometimes find sports participation difficult. If this is a problem, Ragni recommends talking with your healthcare provider about additional treatments and options.

Don't Downplay Injury

Pierce remembers trying to play through injuries when he was younger so that he wouldn't have to miss practices and games. “But that's the worst thing you can do. Luckily for me, none of that set me back. I definitely realized when I would get injured that it was in my best interest to take care of myself,” Pierce says.

Today, Pierce uses DDAVP (desmopressin acetate), a synthetic hormone in the form of a nasal spray, as a pretreatment before intense competitions or after injury. What people with VWD want to avoid is bleeding into the joint. Not only is it painful, but it can also be problematic.

“The long-term consequence is that the blood in the joint is very destructive to the joint itself,” says Herman-Hilker. “You can end up with long-term and permanent joint damage.” Prompt treatment of injuries is important. Herman-Hilker recommends that people with VWD who have sports injuries use the RICE protocol (rest, ice, compression and elevation) and immediately contact their hematologist or HTC to determine if medical treatment is necessary.

Play for the Fun, Health of It

Excelling in sports makes people feel good about themselves and their bodies. Participating in sports builds self-assurance and self-reliance. It improves balance, muscle tone, sleep quality and posture, according to Ragni. “It also contributes to healthy living and reduces obesity, which can contribute to poor health outcomes,” she says. Exercise and sports have special benefits for people with VWD. “Exercise is great for people with VWD

because when you undergo periods of stress, like you do in moderate- to high-intensity exercise, your body actually has a reaction where it releases and increases the level of von Willebrand factor in your blood,” Forsyth says. “Von Willebrand factor and factor VIII are hooked together and circulate in the blood. When you exercise, it causes that von Willebrand factor to be released in the blood, raising the circulating factor level. That's a good thing.”

According to Ragni, some women who engage in sports frequently might gain an additional benefit from the exercise—a reduction in heavy bleeding during their menstrual cycles.

Be Safe But Confident

Megan Procaro, 21, a senior at the University of Pittsburgh who has Type II VWD, says it's easy to be fearful of sports participation. “Once we found out that I had a bleeding disorder, my parents and I were kind of afraid to let me do sports,” Procaro says.

She played some sports, including softball, during middle school and high school, but says she hesitated to give it her all. Now that she has greater understanding of the disorder, Procaro thinks she would be in better shape today if she had participated more when she was younger.

Pierce tries to live proactively, not reactively. “When you are diagnosed with a bleeding disorder, you don't want to look at it as what you can't do. You want to look at it more as, ‘I have VWD, so what can I still do?’”

Plants Help Prevent Inhibitors and Allergic Reactions

Using genetically-modified plants, researchers from two Florida universities are developing a technique that could help prevent treatment-related complications such as inhibitors, an immune reaction that neutralizes infused factor and anaphylaxis, severe allergic reactions, in people with hemophilia B. The lead authors of the study were Dheeraj Verma, PhD, Department of Molecular Biology and Microbiology, College of Medicine, at the University of Central Florida (UCF) in Orlando and Babak Moghimi, MD, Department of Pediatrics, College of Medicine, at the University of Florida (UF) in Gainesville.

Inhibitors result in approximately 25% of patients with hemophilia A and up to 4% of patients with hemophilia B. Clinicians often use immune tolerance (IT) induction to eliminate an inhibitor. By administering daily doses of factor over time, the body begins to tolerate the therapy. The process is similar to desensitization therapy used to treat food and environmental allergies. The technique is less effective in individuals with hemophilia B than in those with hemophilia A. In addition, because of the large amounts of factor used, IT becomes very expensive. The

approach being developed by Verma, Moghimi and colleagues could be more cost effective.

The researchers used a so-called "gene gun" to insert the genetic material that manufactures factor IX (FIX) into chloroplasts, the energy production centers of plants. They then fed the modified plants to mice with hemophilia B for a prolonged time period. Insulated from digestive acids and enzymes by durable plant cell walls, the FIX protein traveled through the stomach and into the small intestines. Once inside the small intestines, bacteria then broke down the cell walls and released the protein, which induced tolerance by the immune system.

"We have made them develop tolerance and removed the allergic part of this treatment," said coauthor Henry Daniell, PhD, a Pegasus professor and University Board of Trustees Chair in the College of Medicine at the UCF.

Later the mice were infused with factor product, which triggered little to no inhibitor responses and no anaphylactic events. "I think this is a milestone - nobody has previously achieved such levels of robust immune tolerance by any means using a

noninvasive procedure," explained Thierry Vandendriessche, PhD, an associate professor of medicine at the University of Leuven in Belgium, who was not involved in the study. He is president of the European Society of Gene Cell Therapy.

Investigators will conduct follow-up studies to test the approach in mice with hemophilia A and then carry out trials in humans using lettuce to produce the therapeutic proteins.

"We're hoping that our research will, in the future, result in better and more cost-effective therapies," said study co-author Roland Herzog, PhD, an associate professor of pediatrics, molecular genetics and microbiology in the UF College of Medicine and a member of the UF Genetics Institute. Herzog received the National Hemophilia Foundation's Career Development Award in 2000.

The study, "Oral Delivery of Bioencapsulated Coagulation Factor IX Prevents Inhibitor Formation and Fatal Anaphylaxis in Hemophilia B Mice," was published in the April 2010 issue of the Proceedings of the National Academy of Sciences.

Source: eScience News, March 30, 2010



Delaware Valley Chapter Support Network

In an effort to increase our service and help to families in areas outside of the central Philadelphia area, we have established five branches of the Delaware Valley Chapter. The purpose of the branches is to help network patients and families affected by hemophilia and von Willebrand Disease (VWD). If you are a patient or parent/s of a patient and would like to socialize with others who share your issues, please contact one of the following team leaders to get involved. These branches meet informally, in private homes, for social events and support. There is no charge for being involved.....just networking with families just like you!! These branches are not open to any person who works or has a family member who works for any industry or company directly or indirectly involved in products or services for patients with bleeding disorders.

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SPECIAL CAMP NEWS

It seems early to be thinking about sending the kids off to camp in the Summer of 2011, but we wanted to give you lots of time to get organized so that you can be sure your child will have a spot for one of the camp sessions. Here's the buzzzzzz!!

THE GOOD NEWS!!

Once again summer of 2011, DVC area kids with bleeding disorders will have an opportunity to attend The Double "H" Hole in the Woods Camp nestled in the mountains in Lake Luzerne, New York. This camp provides an outdoor Adirondack adventure for children with hemophilia each summer. Modeled after actor Paul Newman's Hole in the Wall Gang Camp in Connecticut, the Double "H" Ranch is a place where children with bleeding disorders can participate in a full range of activities and learn leadership skills, as well. The Delaware Valley Chapter will provide FREE transportation for the following two sessions:

SESSION #1: July 18-23 (not confirmed at this time)

SESSION #2: August 3-8 (not confirmed at this time)

FOR AN APPLICATION, CALL THE DVC OFFICE AT 215-885-6500 OR ASK YOUR TREATMENT CENTER TEAM. THE DEADLINE FOR APPLICATION IS APRIL 1, 2011 AND SPACES ARE VERY LIMITED!!

CAMP DRAGONFLY FOREST!!!

Even if your child attends one of the weeks at Double "H" Hole in the Woods Ranch, they may be eligible to attend Camp Dragonfly Forest, right here in the Delaware Valley area!! This camp is free to all campers!! Call Dragonfly Forest directly with questions or to receive an application: 610-298-1820 (deadline is April 1st!!) and check out www.dragonflyforest.org for more details (including on-line registration)!!

Dragonfly Forest for DVC area kids with bleeding disorders: July 7-12, 2011.

CALLING ALL ARTISTS!



Do you have a creative side? Do you like to draw? If you do, we need your hand! We are designing a cover for a Delaware Valley Chapter note card and want it to be a beautiful reflection of local children with bleeding disorders! Here is how you can enter:

Theme: A drawing of what it means to have hemophilia or VWD and what it is about having a bleeding disorder that you are thankful for!

Rules: Submit original artwork on 8 ½ X 11 white paper. Your drawing should fill the entire page from edge to edge and be as colorful and bright as you can make it. On a separate paper include your name, address, age and title of your drawing and brief explanation of what your picture means to you. Drawings can be completed in pencil, crayon, marker, paint or colored pencils. You decide! Be creative!



Who Can Enter: Anyone can enter who is 17 years old or younger. You do not need to have a bleeding disorder to enter. Winning artwork will be incorporated in the note card design and the winner(s) will be announced at the Annual Family Dinner on May 3, 2011. In addition, the top three individuals will be recognized in the Winning Spirit newsletter and all artwork entries will be displayed at the Annual Family Dinner. Selected entries will be displayed on hemophiliasupport.org.

Deadline: All entries must be received no later than April 1, 2011. Any questions, call: 215-885-6500

All entries should be mailed to: National Hemophilia Foundation
222 S. Easton Road, Suite 122, Glenside, PA 19038