



THE WINNING SPIRIT

FALL/WINTER 2013

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NATIONAL HEMOPHILIA FOUNDATION

DELAWARE VALLEY CHAPTER

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Delaware Valley Chapter families at the signing of SB 35.

State legislation was signed into law on July 23, 2013 by Delaware Governor Jack Markell which places limits on the costs to Delawareans for prescription drugs that treat many major health problems, including hemophilia and vonWillebrand Disease. The final provisions of the law (Senate Bill 35) reflected the efforts of the Delaware Valley Chapter of the National Hemophilia Foundation and many different groups within the health care community in Delaware. Governor Markell thanked the organizations and patient advocates who supported the progression of this legislation that now protects the affordability of expensive specialty medicines.

In addition to the Delaware Health Care Commission, which researched the effects of pricing on patient access and care, other groups and organizations involved included the National Hemophilia Foundation, Arthritis Foundation Mid-Atlantic Region, National MS Society - Delaware Chapter, Limestone Medical, Medical Society of Delaware, HIV Consortium and Highmark Blue Cross Blue Shield of Delaware.

By capping co-insurance and co-

payment fees for specialty tier medications, Senate Bill 35 limits the amount that patients will be expected to spend to receive the specialized, and consequently quite-expensive, medications that are necessary for the treatment of their serious long-term health conditions.

“Many of us know someone who is suffering from serious long-term health conditions such as hemophilia, HIV, hepatitis, multiple sclerosis, and lupus, and we are aware of the high personal expense associated with receiving treatment for such conditions,” said Governor Markell. “For Delawareans who are facing challenges like these, this law ensures they will not be unfairly denied access to prescription drugs because of high cost-sharing, and that in obtaining these life-sustaining medications neither they, nor their families, will be forced to endure severe financial strain.”

Under the law, a patient's co-insurance or co-payment fees for specialty tier drugs (including factor concentrates) will be limited to \$150 per month for up to a 30-day supply of any single



**National Hemophilia
Foundation**

DELAWARE VALLEY CHAPTER

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We gratefully acknowledge the pledge of support from the following manufacturers for 2013.

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NEWSLETTER CHANGES COMING

Starting with the 2014 spring issue of *The Winning Spirit*, we will return to a quarterly publication. We tried just doing two issues in 2013, but feedback from you told us that two issues per year just aren't enough to keep us in contact with you. Thanks for letting us know what you like!



**IF YOU WANT THE WINNING SPIRIT NEWSLETTER BEGINNING NEXT
SPRING...READ BELOW!!**

For many years, the Delaware Valley Chapter has been mailing the quarterly newsletter to patients on the Chapter database and, in addition, the area Hemophilia Treatment Centers would separately mail *The Winning Spirit* to their patients. This created duplication for patients who were registered both with the Chapter and their HTC, because they received two newsletters each time...one from the Chapter and then another from their Hemophilia Treatment Center.

Starting with the 2014 spring newsletter, only the Chapter will be mailing *The Winning Spirit* newsletter. If you have been receiving two, you will now only receive one (the one we mail directly to you from the Chapter). If you have been receiving two newsletters, then YOU DON'T NEED TO DO ANYTHING IN ORDER TO CONTINUE TO RECEIVE YOUR ONE NEWSLETTER BECAUSE WE ALREADY HAVE YOUR INFORMATION.

BUT.....if you have been receiving just one newsletter each quarter for the last many years, it was because you were receiving it from your HTC and the Chapter DOES NOT have your contact information.

If you have been receiving just one newsletter each quarter then YOU NEED TO CONTACT THE CHAPTER AND GIVE US YOUR INFORMATION SO WE CAN PUT YOU ON THE CHAPTER NEWSLETTER MAILING LIST. IF YOU DON'T LET US KNOW THAT YOU WANT THE NEWSLETTER AND PROVIDE YOUR MAILING INFORMATION, YOU WILL NO LONGER RECEIVE THE NEWSLETTER.

Take a minute today and contact the Delaware Valley Chapter to have your name added to the newsletter mailing list!! Call: 215-393-3611 or email JoAnn MacDonald at JoAnnM@hemophiliasupport.org. JoAnn will make sure you continue to receive the newsletter and important information about events and issues!! Thanks for being such a loyal reader!!

CHAPTER HAPPENINGS

HERE'S WHAT'S BEEN HAPPENING

JUNE

4: Carlino's Golf Outing

Sponsored by Carlino's Foods in Ardmore, PA, this was a wonderful day of golf, friends and delicious food, all prepared and served by the wonderful employees of Carlino's, of course!! We are grateful once again, to Laura and Pat Carlino and their unbelievable employees who provided this day to us, to support the mission of the Delaware Valley Chapter! A big, big thank you to Kathy and John DiMichele and their beautiful sons, Carlo Luca and Giovanni, who are the inspiration behind this annual event!

8: BBQ Cookoff for a Cure

Rain, rain, go away! Despite the torrid two-inch rainfall the day before the BBQ, the event was again a huge success! A fantastic crowd turned out to enjoy the music of the Steel Creek Band and chow down on outstanding BBQ! Many thanks to the Hatfield American Legion for hosting the event!

14: Living Well with Inhibitors: A Guide for a Healthy Lifestyle, King of Prussia, PA

15: Planning Your Future, Hershey, PA



JULY

13: Living with Hemophilia, Elysburg, PA

AUGUST

4: Lancaster Branch "Bash & Splash"

Families from the DVC Lancaster Branch enjoyed a wonderful day at Refreshing Mountain Camp from noon to 7pm. A big "thank you" to Lorie and Brian Kerstetter, branch leaders, for organizing such a terrific family event!! Food, fun and friendship!

9: Exploring Mental Health in the Hemophilia Community, West Chester, PA

17: Strengthening the Family Communication, New Holland, PA

25: Perk-Up Half Marathon

We enjoyed a cool, beautiful August day on the campus of the prestigious Perkiomen School, host of our 2013 Perk-Up Half Marathon. The event drew some outstanding runners who posted amazing times for the half marathon weaving through rolling hills. Thanks to the Perkiomen Valley Chamber of Commerce, The Perkiomen School and the huge support of local fire police.

SEPTEMBER

6: The Financial Factor: Managing the Cost of Hemophilia, Lancaster, PA

17: DVC Annual Golf Classic

We had a great day at RiverCrest Golf Club in Phoenixville and the weather was perfect! A big "thank you" to CSL Behring for being the event sponsor, once again this year, and to Matt German, Chair of this year's event! Perry Parker, a PGA golfer, was on hand to give a few pointers to the golfers! We appreciated the help of many volunteers who worked all day to make sure every detail was covered! It was a spectacular day for the DVC. Proceeds from this event will support our Patient Services Program this year. Our heartfelt thanks!

20-22: Family Camp

We had a blast of a weekend at Camp Kweebec in Schwenksville, PA. It felt good to come back for our second year at this new site. Everybody had a wonderful weekend of great food, friendship, zip lines, arts and crafts and so much more! We had a magic show on Saturday night provided by the magnificent Mike Miller! We thank the staff at Camp Kweebec for providing such a great weekend for us. See you next year!

28: DVC Walk/Run, Collegeville

What an incredible turnout on this perfect fall day in September! Our dedicated families worked hard to raise money and we were again able to donate \$50,000 to local research for a cure. Special thanks to Pfizer for their support, participation and enthusiasm, and for lending their beautiful campus to us for this event! We also thank our local community of families for their enormous involvement this year!



A big THANK YOU to the Lansdale Catholic girls soccer team and their coach, Joe Campbell. They organized a girls' soccer tournament with each team dressed in a different themed costume. The girls raised \$945.00 for the DVC! Thank you.

COMING UP

DECEMBER

14 Annual Holiday Party, Cannstatter's, Philadelphia

JANUARY

11: After Holiday Party, Shady Maple Smorgasbord, Lancaster

FEBRUARY

22 Bowling for Fun, Thunderbird Lanes, Philadelphia

MARCH

29 Fashion Show, Whitmarsh Valley Country Club, LaFayette Hill

MAY

6 Annual Family Dinner, Hilton Hotel, City Avenue

17 Broad Street ReRun, Lansdale

FYI

IMPORTANT

Again this year, The Delaware Valley Chapter was very proud to be able to award \$50,000.00 to support important research specific to hemophilia or vonWillebrand Disease. Two checks were presented at the Collegeville Walk on Saturday, September 28, 2013 to support two important research projects at The Children's Hospital of Philadelphia. Following is a description of each research project.

The first study, by Valder Arruda, MD, PhD is entitled, "In Depth Characterization of Immune Responses in Hemophilia." This project will characterize both humoral responses and cellular responses to clotting factors. This study has the potential to provide insights into the risk of inhibitor formation and the effect of antibodies that prevent full recovery of normal half-life of infused proteins. Award: \$25,000.00

The second study, by Denise E. Sabatino, PhD is entitled "Enhancing Factor VIII Gene Expression for Hemophilia A Gene Therapy." This project will deliver optimized factor VIII using gene therapy in hemophilia A dogs. Award: \$25,000.00

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 four 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....just networking with families like you!! These branches are not open to any person who works for 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.

Delaware Branch
Gail & Luke Vannicola
302-598-4632

Lititz/Lancaster Branch
Lorie & Brian Kerstetter
717-626-9679

Mount Carmel Branch
Jolene & Sam Scicchitano
570-339-4137

Hershey/Harrisburg Branch
Amanda and Tom Gallagher
717-361-1886

KEY FEATURES OF THE AFFORDABLE CARE ACT IN 2013 AND 2014

On March 23, 2010, President Obama signed the Affordable Care Act. The law puts in place comprehensive health insurance reforms that will roll out over four years and beyond. The following information is available on www.hhs.gov/healthcare.

OVERVIEW OF THE HEALTH CARE LAW

2010: A new Patients' Bill of Rights goes into effect, protecting consumers from the worst abuses of the insurance industry. Cost-free preventive services begin for many Americans.

2011: People with Medicare can get key preventive services for free and also receive a 50% discount on brand-name drugs in the Medicare "donut hole."

2012: Accountable Care Organizations and other programs help doctors and health care providers work together to deliver better care.

2013: Open enrollment in the Health Insurance Marketplace begins on October 1st.

2014: All Americans will have access to affordable health insurance options. The Marketplace will allow individuals to compare health plans on a level playing field. Middle and low-income families will get tax credits that cover a significant portion of the cost of coverage. And the Medicaid program will be expanded to cover more low-income Americans.

Here is a summary of what has happened in 2013 and what is coming in 2014

2013

IMPROVING QUALITY AND LOWERING COSTS

- **Improving Preventive Health Coverage.** To expand the number of Americans receiving preventive care, the law provides new funding to state Medicaid programs that choose to cover preventive services for patients at little or no cost. Effective January 1, 2013.
- **Expanding Authority to Bundle Payments.** The law establishes a national pilot program to encourage hospitals, doctors, and other providers to work together to improve the coordination and quality of patient care. Under payment "bundling," hospitals, doctors, and providers are paid a flat rate for an episode of care rather than the current fragmented system where each service or test or bundles of items or services are billed separately to Medicare. For example, instead of a surgical procedure generating multiple claims from multiple providers, the entire team is compensated with a "bundled" payment that provides incentives to deliver health care services more efficiently while maintaining or improving quality of care. It aligns the incentives of those delivering care, and savings are shared between providers and the Medicare program. Effective no later than January 1, 2013.

INCREASING ACCESS TO AFFORDABLE CARE

- **Increasing Medicaid Payments for Primary Care Doctors.** As Medicaid programs and providers prepare to cover more patients in 2014, the Act requires states to pay primary care physicians no less than 100% of Medicare payment rates in 2013 and 2014 for primary care services. The increase is fully funded by the federal government. Effective January 1, 2013.
- **Open Enrollment in the Health Insurance Marketplace Begins.** Individuals can buy affordable and qualified health benefit plans in this new transparent and competitive marketplace. Effective October 1, 2013.

2014

NEW CONSUMER PROTECTIONS

- **Prohibiting Discrimination Due to Pre-Existing Conditions or Gender.** The law implements strong reforms that prohibit insurance companies from refusing to sell coverage or renew policies because of an individual's pre-existing conditions. Also, in the individual and small group market, the law eliminates the ability of insurance companies to charge higher rates due to gender or health status. Effective January 1, 2014.
- **Eliminating Annual Limits on Insurance Coverage.** The law prohibits new plans and existing group plans from imposing annual dollar limits on the amount of coverage an individual may receive. Effective January 1, 2014.
- **Ensuring Coverage for Individuals Participating in Clinical Trials.** Insurers will be prohibited from dropping or limiting coverage because an individual chooses to participate in a clinical trial. Applies to all clinical trials that treat cancer or other life-threatening diseases. Effective January 1, 2014.

IMPROVING QUALITY AND LOWERING COSTS

- **Making Care More Affordable.** Tax credits to make it easier for the middle class to afford insurance will become available for people with income between 100% and 400% of the poverty line who are not eligible for other affordable coverage. (In 2010, 400% of the poverty line comes out to about \$43,000 for an individual or \$88,000 for a family of four.) The tax credit is advanceable, so it can lower your premium payments each month, rather than making you wait for tax time. It's also refundable, so even moderate-income families can receive the full benefit of the credit. These individuals may also qualify for reduced cost-sharing (copayments, co-insurance, and deductibles). Effective January 1, 2014.

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PREPARING FOR HEALTHCARE REFORM

GET YOUR DUCKS IN A ROW WHILE ACA ROLLOUT CONTINUES

By January W. Payne

Published September 2013 in *HemAware*, a publication of the National Hemophilia Foundation

As key provisions of the Affordable Care Act (ACA) go into effect in 2014, people in the bleeding disorders community with and without health insurance coverage will likely have questions about how they will be affected. Changes include a mandate for small employers to provide insurance and a move to link physician payments to quality of care.



The answer to how ACA affects you varies, depending on your existing coverage and costs. Some may see very little impact on their health insurance. Others may experience changes, especially if they sign up for plans offered under the new Health Insurance Marketplace, an option that will be offered for the first time in 2014. Regardless, there are several things you should keep in mind to stay informed on what's coming, and how it affects you and your family:

Understand your current coverage. Know whether you are currently covered by a health maintenance organization (HMO), preferred provider organization (PPO) or point-of-service (POS) health insurance plan. The type of plan your employer offers can change, even if your insurance provider remains the same. "You may be offered an HMO rather than a POS plan, for example," says Marla Feinstein, policy analyst at the National Hemophilia Foundation (NHF).

Then get a copy of your policy. If you have employer-sponsored coverage, your company's human resources (HR) department can help you obtain a copy of your insurance policy. "Get a detailed plan summary, not a brochure," Feinstein says. That same advice goes for an individual plan purchased on your own: Contact your insurer to request a detailed copy of your plan information.

Investigate whether it's worthwhile to find a new policy. The newly relaunched HealthCare.gov consumer website, run by the US Department of Health and Human Services (HHS), helps consumers evaluate healthcare options and make educated decisions about coverage. HHS also has a call center available 24 hours a day: 800.318.2596.

HHS's online support provides only educational resources right now, but during the open enrollment period from October 1, 2013, through March 31, 2014, consumers will be able to create accounts, apply for and compare plans, and evaluate options. Coverage is available starting January 1, 2014. If

your state is operating its own marketplace or joining a partnership, HealthCare.gov will direct you to the appropriate website. The website also includes a chat feature, allowing real-time assistance with certified staff.

Pre-existing conditions no longer disqualify consumers. Starting in 2014, health insurers cannot deny coverage to an adult applicant because of a pre-existing medical condition. (The ACA provision preventing denial of health insurance to anyone under age 19 due to pre-existing conditions took effect in

2010.) The Pre-existing Condition Insurance Plan (PCIP), a temporary program to cover those who do not qualify for other plans because of pre-existing conditions, has been in place since March 2010 as a stopgap measure.

Before switching insurance plans, contact your HTC. Check with your HTC to make sure the plan you're considering allows you to continue to visit that HTC and stay in network, Feinstein says.

Confirm coverage of clotting factor before agreeing to a new plan. "Clotting factor is extremely expensive and can cost \$300,000 per person a year or more," says Johanna Gray, MPA, vice president of Washington, DC-based CRD Associates, and an NHF policy advisor. "It's also important to know how clotting factor is covered: Is it covered under your insurance policy's medical benefit or the pharmacy benefit? Who are the in-network pharmacy providers? Finding answers to these questions will help you anticipate and manage your out-of-pocket expenses."

Ask about copayments and deductibles. Consider changing plans if your copay or co-insurance has increased or will significantly change in the future. "If any dollar amount has changed, you might have to re-evaluate your personal finances," says Feinstein. "If the amount you are paying out of pocket has increased, you might want to weigh the options being offered for other plans."

Finally, there may be no change to your plan—and that's OK. It's always good to review your insurance coverage to know what you have. But, Feinstein says, "if there is nothing wrong with your current coverage, why would you change it?"

WHAT YOU NEED TO KNOW AND WHAT YOU NEED TO DO TO APPLY FOR INSURANCE THROUGH YOUR STATE'S HEALTH INSURANCE EXCHANGE MARKETPLACE APPLICATION CHECKLIST

This list was taken from www.healthcare.gov

When you apply for coverage in the Health Insurance Marketplace, you'll need to provide some information about you and your household, including income, any insurance you currently have, and some additional items.

Use the checklist below to help you gather what you need to apply for coverage. Open enrollment starts October 1, 2013 for coverage starting as early as January 1, 2014. Open enrollment ends March 31, 2014.

- Social Security Numbers (or document numbers for legal immigrants)
- Employer and income information for every member of

your household who needs coverage (for example, from pay stubs or W-2 forms—Wage and Tax Statements)

- Policy numbers for any current health insurance plans covering members of your household
- A completed Employer Coverage Tool for every job-based plan you or someone in your household is eligible for. (You'll need to fill out this form even for coverage you're eligible for but don't enroll in.) To view the form and for additional information, go to www.healthcare.gov.

Stay up-to-date about the Marketplace. Visit www.healthcare.gov/subscribe to get email or text updates that will help you get ready to apply.

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KEY FEATURES OF THE AFFORDABLE CARE ACT

- **Establishing the Health Insurance Marketplace.** Starting in 2014, you will be able to buy health insurance directly in the Health Insurance Marketplace. Individuals can buy affordable and qualified health benefit plans in this new transparent and competitive insurance marketplace. The Marketplace will offer you a choice of health plans that meet certain benefits and cost standards.

INCREASING ACCESS TO AFFORDABLE CARE

- **Increasing Access to Medicaid.** Americans who earn less than 133% of the poverty level (approximately \$14,000

for an individual and \$29,000 for a family of four) will be eligible to enroll in Medicaid. States will receive 100% federal funding for the first three years to support this expanded coverage, phasing to 90% federal funding in subsequent years. Effective January 1, 2014.

- **Promoting Individual Responsibility.** Under the law, most individuals who can afford it will be required to obtain basic health insurance coverage or pay a fee to help offset the costs of caring for uninsured Americans. If affordable coverage is not available to an individual, he or she will be eligible for an exemption. Effective January 1, 2014.

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STATE LEGISLATION SIGNED

specialty tier drug. Patients will also be able to request an exception to obtain a specialty drug that would not otherwise be available on a health plan formulary. The bill goes into effect on January 1, 2014.

"This law is a needed protection, not only for people with bleeding disorders, but for others in Delaware with high-cost chronic diseases who need expensive medicines to sustain their lives," said Ann Rogers from the Delaware Valley Chapter/ NHF. "It was a privilege to be a part of this three-year effort with so many other organizations. Senator Margaret Rose Henry, sponsor of the legislation, was the best example of a state legislator. She led a fair and transparent process right from the beginning. She never wavered on her commitment to regulate high cost-sharing for expensive medicines. She

truly effected landmark state legislation in 2013 and was honored by the National Hemophilia Foundation at its Annual Meeting in Anaheim, California in October as the 2013 Advocate of the Year.

She will never be forgotten for her strength and leadership as she tackled a big problem. In the end, SB 35 was a consensus bill and not opposed by the insurance industry in Delaware."

The Delaware Valley Chapter of the National Hemophilia Foundation will honor Senator Margaret Rose Henry at the 2014 Chapter Annual Family Dinner on Tuesday, May 6, 2014.



GET COVERED: A GUIDE TO THE HEALTH INSURANCE MARKETPLACE

Here's a quick rundown on the most important things to know about the Health Insurance Marketplace, sometimes known as the health insurance "exchange." For additional information, go to www.healthcare.gov.

The new Health Insurance Marketplace helps uninsured people find health coverage. When you fill out the Marketplace application you will be told if you qualify for:

Private insurance plans. You will be told whether you qualify for lower costs based on your household size and income. Plans cover essential health benefits, pre-existing conditions and preventive care. If you don't qualify for lower costs, you can still use the Marketplace to buy insurance at the standard price.

Medicaid and the Children's Health Insurance Program (CHIP). These programs provide coverage to millions of families with limited income. If it looks like you qualify, your information will be shared with your state agency and they'll contact you. Many but not all states are expanding Medicaid in 2014 to cover more people.

No matter what state you live in, you can use the Marketplace. Some states operate their own Marketplace. In some states, the Marketplace is run by the Federal government (PA). You can find the Health Insurance Marketplace in your state at: www.healthcare.gov.

Most people must have health coverage in 2014 or pay a fee. If you don't have coverage in 2014, you'll have to pay a penalty of \$95 per adult, \$47.50 per child, or 1% of your income (whichever is higher). The fee increases every year. Some people may qualify for an exemption to this fee.

You're considered covered if you have Medicare, Medicaid, CHIP any job-based plan, any plan you bought yourself, COBRA retiree coverage, TRICARE, VA health coverage or some other kinds of health coverage.

If you're eligible for job-based insurance, you can consider switching to a Marketplace plan. But you won't qualify for lower costs based on your income unless the job-based insurance is unaffordable or doesn't meet minimum requirements. You also may lose any contribution your employer makes to your premiums.

If you Medicare, you're considered covered and don't have to make any change. You can't use the Marketplace to buy a supplemental or dental plan.

Marketplace open enrollment ends March 31, 2014. If you enroll by December 15, 2013, coverage can begin as soon as January 1, 2014.

Questions? Call 24 hours a day, 7 days a week: 1-800-318-2596 (TTY: 1-855-889-4325)

HOLIDAY GIVING AND ANNUAL APPEALS

If you are like most people, beginning in November each year, you receive an endless stream of letters in the mail, seeking your year-end donation, particularly around the holidays. Some thoughts from the DVC....

Ideally, we would like to touch every individual who, through their generosity, has continued to support the Delaware Valley Chapter and its mission of providing programs, services and resources to individuals affected by hemophilia and vonWillibrand Disease locally. It is our supporters (YOU!!) who know how we help local families affected by bleeding disorders throughout the year....and we want you to know how much your support means to our mission of service to more than 2,700 local patients in the Delaware Valley area.

Throughout this holiday season, the DVC will be taking steps



to get to know you better. Getting to know you, means using the telephone, cards, letters and other electronic means like email, to keep you informed and to express our sincere thanks for your ongoing help and support. So don't be surprised if one of our dedicated volunteers gives you a call and says "I'm calling from the DVC...." We will be reaching out to you because we are proud and eternally grateful to have you as part of our family, a family that is supportive and caring... a family that responds to the unique needs of the bleeding disorders' community. And ... as a member of our family, we want to know you better! This holiday season, when making your charitable-giving decisions, we hope you will think of our local families who rely on the services and resources provided by the Delaware Valley Chapter every day of the year. With your continued support, we will ensure the DVC provides a *Lifeline for a Lifetime*.