KEY ISSUES FOR PEOPLE WITH BLEEDING DISORDERS IN PENNSYLVANIA AND DELAWARE

SPECIALTY TIER DRUG PRICING

The Pennsylvania and Delaware State General Assemblies have both taken legislative action regarding "specialty tier drug pricing." More than 2,700 patients with bleeding disorders in both states stand to benefit from the actions being taken right now!! Here's what's happening!

One way PA and DE insurers are trying to reduce the costs they pay for expensive medicine is to implement "specialty tier drug pricing" for specialty drugs. Factor concentrates and some other medicines needed to manage bleeding disorders are considered "specialty drugs."

Specialty drugs are high-cost medicines that cost more than $600/month. When a tiered system is used by an insurer, patients are required by their insurance plan to pay a percentage of the total charge for the drug (referred to as co-insurance), rather than a fixed amount (referred to as a co-payment). Insurance plans can include this requirement in the medical and/or pharmacy benefit

The primary purpose of specialty tiers is to share the cost of particularly expensive drugs between patients and health insurers. Each insurance plan develops its own list of specialty tier drugs. Changes to that list can occur at any point in the plan year.

Hemophilia factor concentrates are typically placed on Tier 3 or 4 with a co-insurance of 25%-33% of the cost of the drug. As an example, an adult patient with severe hemophilia needing $40,000 of life-sustaining factor concentrate each month would be responsible for at least $10,000 in out-of-pocket costs every month.

Several states have banned or restricted the use of specialty tiers and others have introduced legislation calling for a study to determine the impact of this insurance practice on people in their state. Pennsylvania Senator Bob Mensch has introduced Senate Resolution 70 calling for the Legislative Budget and Finance Committee to study the effects of specialty tier drug pricing on thousands of patients in Pennsylvania who rely on high-cost drugs to sustain their lives. The committee will report its findings with any recommendations to the state Senate by January 2014. SR 70 applies to anyone taking a specialty drug (not just people with hemophilia and vWD).

Delaware is a bit further along with its efforts. DE Senator Margaret Rose Henry introduced a bill in 2011 (SB 137) which called for a study of the issue. The study was conducted and the Delaware Valley Chapter participated as a member of the study committee. The recommendation of the committee at the conclusion of the study was that specialty tier drug pricing needed to be regulated with caps placed on out-of-pocket costs required by insurers.

Delaware Senator Margaret Rose Henry has introduced Senate Bill 35, to regulate the amount of out-of-pocket costs (co-insurance) that an insurer can require for specialty drugs. This bill, if passed, will limit the dollar amount someone must pay for specialty drugs each month, including factor concentrates.

How You Can Help

We need to let our state Senators in Delaware and Pennsylvania know that we want their support on this very important issue. Please help!

If you are a Delaware family, contact members of the Delaware Senate and ask them to contact Senator Margaret Rose Henry and pledge their support of SB 35 which regulates the amount of drug cost-sharing required by commercial insurers in Delaware.

If you are a Pennsylvania family, contact members of the Pennsylvania Senate and ask them to contact Senator Bob Mensch and pledge their support of SR 70 which calls for a study on the impact of specialty tier drug pricing in Pennsylvania.

To find out the contact information for writing or calling state Senate members in Delaware or Pennsylvania, contact the DVC office (215-393-3611) or go to www.legisl.state.pa.us or www.legis.state.de.us.

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National Hemophilia Foundation
Delaware Valley Chapter

THE WINNING SPIRIT

SPRING/SUMMER 2013
VOLUME 20 #1 NEWSLETTER
NATIONAL HEMOPHILIA FOUNDATION
DELAWARE VALLEY CHAPTER

IN THIS ISSUE

Have you been feeling out of the loop?

Missing your DVC Newsletter?

Catch up by viewing the archive of our monthly DVC email newsletters: http://www.hemophiliasupport.org/archive.html

Better yet, sign-up for these email newsletters. Send us your email to hemophilia@navpoint.com.

In an effort to reduce the costs of printing and mailing in the future, the Delaware Valley Chapter would like to send more information through email and less through traditional mailings. Even though you have been receiving the *Winning Spirit* newsletter, you may be receiving it each time because your HTC mails it to you. The Chapter may not have your contact information. Please send your complete contact information to: hemophilia@navpoint.com. Include your email, so we can make sure you get important information in a timely manner!

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Graphic Artist: www.chaley.com

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

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HEMOPHILIA PATIENT AND PROGRAM SUPPORT, INC. WELCOMES THE 2013 PARTICIPATING COMPANIES

Each spring, we introduce our readers to the HPPS participating companies for the current year!! Each of these companies provides pharmacy and home supportive services to local patients affected by bleeding disorders and all have qualified as a 2013 participating company. Each company meets the very high standards of service set by Hemophilia Patient and Program Support, Inc (HPPS).

2013-2014 HPPS PARTICIPATING COMPANIES

Walgreens

NCHS

CORAM specialty infusion services
An Apria Healthcare Company

accredo®

Meet these companies by going to our website www.hemophiliasupport.org and clicking on the companies' logos. You will be linked directly to their site where you will find detailed information on the services that each company provides. Be an educated consumer and get the information you need to make informed decisions about what you need in a pharmacy. If you or your family member has a bleeding disorder and you haven't registered with the HPPS program in the past, e-mail your contact information to hemophilia@navpoint.com. By registering, you will be informed of important issues, events and programs throughout the year. The Chapter has resources that may be of help to you.

Hemophilia Patient and Program Support, Inc. is dedicated to providing support to patients and programs within the geographic boundaries of the DVC. Become a member today!!

FYI

IMPORTANT
Information Regarding Your Newsletter Mailing

You may be receiving this newsletter via your Treatment Center. If you would like to receive your *Winning Spirit* via email, contact the Delaware Valley Chapter at 215-393-3611 or email hemophilia@navpoint.com and let us know. Provide the following information in your email: name, current mailing address, home and cell phones and the email address you would like us to use. You will begin to receive your newsletter via your email.

CHAPTER HAPPENINGS

2012 FALL/WINTER UPDATE

OCTOBER

6 & 14: 5K RUNS & WALKS

Because of the hard work and the generosity of so many, we raised over $120,000 to benefit the programs and services of the Delaware Valley Chapter at the 2012 Walks and Runs at two locations! From the proceeds, $50,000 was contributed to research:

- $35,000 to The Children's Hospital of Philadelphia for gene therapy research
- $15,000 to The Hospital of the University of Pennsylvania for a pilot study of hemophilia

Heather Thompson chaired the Third Annual I Can Run 5K and Family Walk, which was held on October 6th on the Collegeville campus of the event sponsor, Pfizer. Eighteen teams participated in this great event! The First Annual I Can Run 5K and Family Walk in Lancaster took place on October 14th, chaired by Amanda Heisey. Nine teams participated. It was so nice to have the Lancaster area families be a part of the event this year!

Over the last three years, the walk teams have raised more than $350,000 in support of the mission of the Delaware Valley Chapter. We want to thank everyone who contributed to these events. All your hard work and commitment is recognized and appreciated. We cannot do this without all of you, from the kids who were out selling lemonade to raise money, to the Vespe

family who held a huge beef and beer fundraiser! We hope to see everyone again next year, so start getting your teams ready!

DECEMBER

1: CHAPTER HOLIDAY PARTY FOR THE PHILADELPHIA AREA!

Ho! Ho! Ho! A great day and so much fun!

JANUARY

5: CHAPTER AFTER-HOLIDAY PARTY FOR CENTRAL PA

A great big "thank you" to Lorie and Brian Kerstetter and their two awesome sons, Corey and Evan, who organized this wonderful celebration!

2013 SPRING UPDATE

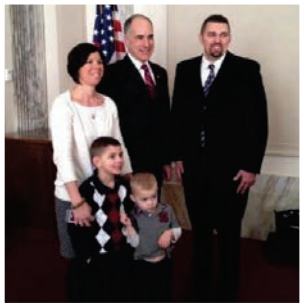
FEBRUARY

23: BOWLING FOR FUN

We had the best time at this family event!! Parents and kids all over the place with lots of prizes and pizza!! Thanks to Pat and Chuck Felthaus and Cheryl and Keith Littig for organizing all the details. What a blast!!

28: NHF WASHINGTON DAY

DVC area families joined families from around the country in Washington, DC, to speak with federal legislators about hemophilia and vonWillebrand Disease. This year, we focused our discussions on continued federal support for the HTCs in the



United States, Specialty Tier Drug Pricing and the Affordable Care Act (ACA). Thanks to all DVC volunteers who took the time to participate in this important day. Your voices were heard!

MARCH

8-10: VWD WOMEN'S RETREAT

Women in families affected by vonWillebrand Disease enjoyed a weekend of education and relaxation at the Women's VWD Retreat on the Hill held at the ACE Conference Center in Lafayette Hill, PA. The weekend was packed with information and networking opportunities. A special "thank you" to CSL Behring for providing a generous educational grant that made this weekend possible.

APRIL

9: AWARENESS DAY IN THE PA STATE CAPITOL

Families visited with state legislators and discussed funding for the PA hemophilia programs, specialty tier drug pricing and The Affordable Care Act. A special "thank you" to all families and volunteers who participated!

13: ANNUAL FASHION SHOW & LUNCHEON

Guests enjoyed a beautiful spring day and the latest fashions from Gap and Gap Kids, Banana Republic, J.Jill and Country Brides and Gents. A enormous thank you to the wonderful volunteer models, including kids and moms affected by bleeding disorders! A special "thank you" to Nanette Germain, the event Chairperson and to the Ladies Committee for organizing this wonderful event!

MAY

7: ANNUAL FAMILY DINNER

Many Hearts, One Home was the theme for this year's event. Four hundred family members and hemophilia program staff spent a very special evening together at the Hilton Hotel on City Avenue. Highlights of the evening included a *Cardiovascular Update for Adults with Hemophilia,* by Patrick Fogarty, MD (UPENN Hemophilia Program), *Hemophilia Care…Then and Now,* by Regina Butler, RN (CHOP Hemophilia Program) and *A Family Approach to Care* by Anne Bole, SW (St. Chris Hemophilia Program). The keynote speaker, Jeanne White Ginder, mother of Ryan White, presented *The Legacy of Ryan White.* Her presentation touched our hearts in a very special way. It was an evening we will never forget!

11: BROAD STREET RERUN

WOW!! What a fantastic time! An even the Philly Phanatic was there! Over 500 runners and 150 kids hit the streets of Lansdale to participate in the ½ mile kid run and 5 mile run. What an amazing outpouring of support from the local Lansdale community. A huge thank you to all the runners, volunteers and sponsors who helped make this day a SUCCESS!!

HERE'S WHAT'S COMING UP!!

For detailed information on the following events or to REGISTER, call the DVC office (215-393-3611) or e-mail: ellenk@emophiliasupport.org or register through the Chapter website: www.hemophiliasupport.org

JUNE

4: Carlino's Golf Outing

8: BBQ Cookoff for a Cure

AUGUST

25: Perk-Up Half Marathon

SEPTEMBER

17: DVC Annual Golf Classic

20-22: Family Camp

28: DVC Walk/Run, Collegeville

NOVEMBER

16: DVC Walk/Run, Lancaster

TAKING CONTROL OF YOUR HEALTH: A TESTIMONIAL OF PERSEVERANCE

Maintaining a balanced diet, staying physically fit and managing stress are important for everyone, especially for those living with a bleeding disorder. A regular, safe exercise program protects the joints and can even help decrease bleeding episodes.

Matt Stinger, 29, a patient with hemophilia, a registered nurse, and participant in *HFA's 2012 Gears for Good* annual bike ride, talks about how exercise is the key to staying healthy, protecting joints, and decreasing bleeding episodes.

Were you active growing up and throughout college?

As a kid, I always swam and hiked with my family to stay healthy. After graduating from nursing school in 2006, I found that I wasn't as active as I once was. I was working in the emergency room and was constantly on my feet, but on days off, I found myself on the couch, not motivated to work out. I fell into a period where I wasn't really doing much of any physical activity. Looking back, I noticed that I was getting increasingly more spontaneous bleeds, especially in my joints in 2008. I had a left elbow synovectomy. I recovered from surgery by going through a lot of physical therapy, but quickly found myself back in my old routine.

Was there something that helped you to make the decision to start living a healthy lifestyle again?

During the time I wasn't active, my brother kept bugging me to join a gym, but I would always find excuses why it wasn't the right time. Finally, I decided to buy a gym membership in February of 2012. After going a couple of times, I started to notice a difference and it soon became addicting. It was awesome. I lost between 35-40 pounds within the first 6 months and the passion I had for life was back.

What differences have you noticed since you started living a healthy lifestyle again?

Aside from my physical appearance and increase in confidence, I've noticed that I bleed less. When I was less active and heavier, I was infusing more often due to frequent bleeding episodes, but since I've lost the weight, I now use less medication and make sure that I follow my treatment regimen. If I think that I have a possible injury, I stop, infuse, and rest for a couple of days. Listening to your body is key to staying on top of your condition.

What do you now do to maintain your healthy lifestyle?

I swim, bike and work on core and muscle strengthening three to four times a week. I travel often but find ways to make sure I get my workouts in. I don't want to lose the progress that I made and on days that I can't work out, I try hard to choose healthy food options and cook my own meals.

Now that you are living a healthy lifestyle, what keeps you motivated?

I stay motivated and on track because I now know the consequences of living a sedentary and unhealthy lifestyle. There are little things I do such as taking the stairs or parking a further distance away and I make sure whether it's swimming, biking or muscle strengthening, that I fit it into my schedule. It also makes a difference if you have someone to workout with to help keep you motivated.

I have been using HFA's Get in Gear app to track my accomplishments over the past year. The app has an award-based system that rewards you with badges based on the duration and distance of your workouts over time. I just received the 100-mile swimmer badge and as silly as it sounds, I was on a mission to obtain as many of these badges as I could. Staying fit is one of the best things that you can do for yourself and make sure to find a routine that works for you. My hemophilia has, in turn, played less and less of a role in my life since getting back in shape.

What advice would you give to someone with a bleeding disorder reading this that was in the same place you were?

Having an overall healthy lifestyle is essential. You won't experience change overnight, but it will happen if you stick with it. When you are bleeding less, you can do more and be held back less. It's worth all the time invested because it makes you stronger in your physical appearance, attitude and mental stability.

Everyone's body is different, but listen to yourself and tailor your workouts accordingly. If your ankles aren't in the best shape, then you probably shouldn't run, but don't let that stop you from doing something. Use an elliptical, swim or do anything that you enjoy. Remember, it's not what you can't do in life; it's what you can do.

Previous article taken from *Community Voices: Dateline Federation,* a publication of the Hemophilia Federation of America, Spring 2013 edition.

End Note: Matt is a DVC member and was raised in Hatboro, PA. He is "one of our very own!

FYI

Life Insurance. . . Can You Get It?

Obtaining life insurance, for a person with hemophilia, can be a daunting task, to say the least. If you have been able to purchase life insurance through a broker or directly from an insurance company and would be willing to share that information with the Chapter, it might help someone else in our community. Let us know what has worked for you! We'll pass it on…..

FYI

The Chapter is looking for volunteers who might be able to give a little time to help with projects in the Chapter office, working on events, doing errands, making phone calls or just being an extra pair of hands when we have a need! If you have some time and think you can help, call the Chapter office (215-393-3611). You'll reap great rewards by being a part of a great organization! And, most of all……..we really need YOU!!

GENOTYPING FOR PROGRESS

My Life, Our Future aims to unlock hemophilia

During the past 20 years, advances in hemophilia treatment, including recombinant factor therapy, have allowed people with hemophilia to take greater control of their disorder. While the goal of safe and effective treatment through DNA technology has been realized, there is still much to be done to improve knowledge about the connection between the genetic cause of hemophilia and its management.

At the National Hemophilia Foundation's (NHF's) 64th Annual Meeting in November 2012 in Orlando, Val D. Bias, CEO, announced the launch of ***My Life, Our Future,*** a program that will help people with hemophilia and their families understand the unique aspects of their bleeding disorders by offering them free or low-cost genetic testing, also known as genotyping. The initiative is the result of a partnership between NHF, the American Thrombosis and Hemostasis Network (ATHN), the Puget Sound Blood Center (PSBC) and Biogen Idec Hemophilia. Genotyping may provide individuals and their physicians with insight into bleeding severity, inhibitor risk and carrier status, which can help improve their knowledge of the disorder and their care. It will also generate data that may advance scientific research on hemophilia and potentially lead to new treatments in the future.

What Is Genotyping?

Genotyping is the process of identifying the specific genetic mutation responsible for an individual's disorder, in this case, hemophilia. "DNA is extracted from the blood to determine the factor VIII or IX sequence," says Barbara Konkle, MD, medical director for the Hemostasis Reference Laboratory, and director of clinical and translational research at PSBC. "This is then compared to normal factor VIII or IX sequence to identify the specific mutation."

Because of the large number of mutations associated with the disorder, genotyping is especially valuable in hemophilia. "There are more than 2,500 identified mutations for hemophilia A and more than 1,000 for hemophilia B. This is in contrast to many other genetic disorders where one mutation is always responsible," says Marion Koerper, MD, medical advisor to NHF. Genotyping can identify the specific genetic mutation causing hemophilia in up to 98% of individuals who have hemophilia A and more than 99% of individuals who have hemophilia B.

The Benefit to Patients

One of the many benefits of genotyping for hemophilia is its potential to predict inhibitor risk. Extensive research has already suggested that certain mutations are associated with higher risk for inhibitor formation. For example, in severe hemophilia A, individuals with inversion mutations or large deletions may have a higher risk of developing an inhibitor. Genotyping may also provide information about bleeding severity, which varies widely even among individuals with the same type of hemophilia. Identifying patients' genotypes may help physicians individualize treatment plans for them in the future. "If physicians can better understand someone's bleeding pattern or inhibitor risk, they can modify the therapy and care in an effort to provide the best outcome for the patient," says Konkle.

Moreover, these tests can also identify carriers, aid in early family planning, and possibly improve outcomes during childbirth and after delivery. "If a woman knows she is going to have a child with hemophilia, she and her family can better prepare for delivery and care," says Bias, who has hemophilia B and has been genotyped. He notes that genotyping has been a valuable tool for his extended family. The women in his family were genotyped when considering pregnancy. Genotyping has allowed them to embrace their family's bleeding disorder, Bias says.

Addressing a Long-Unmet Need

Despite the benefits of genotyping, a survey of healthcare providers conducted by ATHN in October 2012 shows that only 20% of people with hemophilia in the US have been genotyped. The majority of respondents cited the cost of testing and insurance coverage restrictions as the main barriers. But the community's interest in genotyping is high. In a 2012 survey of more than 1,000 hemophilia community members conducted by NHF, more than 75% said they would take advantage of free or low-cost genotyping if it were available. ***My Life, Our Future*** addresses this obstacle and will eventually enable most people with hemophilia in the US to be genotyped at no or very low cost.

"For the past 15 years, we in the hemophilia community have been advocating for widespread access to genotyping for patients and carriers, but until now, the combination of resources and expertise was not available," says Glenn Pierce, MD, PhD, senior vice president, global medical affairs for Biogen Idec and chief medical officer of Biogen Idec Hemophilia. As a two-time past president of NHF's board of directors, Pierce remembers when NHF's Medical and Scientific Advisory Council (MASAC) passed a resolution in 1999 recommending genotyping as part of comprehensive care for individuals with inherited bleeding disorders. MASAC also recommended that NHF identify funding sources to make the service widely available. In 2003, a resolution was introduced in Congress to increase funding for research for bleeding disorders and facilitate genotyping, but it was not enacted. In 2005, the Centers for Disease Control and Prevention provided access to genotyping to a subset of patients as part of a study of inhibitors, but was unable to offer a national genotyping program due to logistical and funding challenges.

My Life, Our Future has been made possible through the collaboration of four leaders in the hemophilia community, each of which plays a crucial role in the program. ATHN, a not-for-profit organization representing more than 130 hemophilia treatment centers (HTCs), is ensuring the collection and secure storage of data and preparing HTCs to implement the service. NHF is educating patients and the community about the program through its chapter network and resources. PSBC, a state-of-the-art laboratory and research institution with expertise in hemophilia mutation analysis, is conducting the secure genetic testing and analysis. Biogen Idec Hemophilia, a biotechnology company committed to empowering people with hemophilia, is providing funding and scientific expertise for the partnership through at least 2014. Thereafter, the project may be extended to provide greater access to those affected by hemophilia. In November 2012, MASAC adopted a recommendation that all individuals with hemophilia and their affected family members participate in ***My Life, Our Future.***

My Life, Our Future: How It Works

The goal of ***My Life, Our Future*** is to genotype as many people in the US affected by hemophilia as possible. To ensure a smooth national rollout, the program is being piloted in spring 2013 in at least 10 HTCs that will offer free or very-low-cost genotyping to existing patients.

Once the results from the pilot sites have been reviewed and any needed adjustments made, the genotyping service will be expanded to other HTCs across the country. Plans are to eventually expand the service to potential carriers.

During the pilot phase and after, individuals with hemophilia A or B who want to access the genotyping service will only need to visit their participating HTC for a blood test. The HTC will send

the blood sample to PSBC's specialized hemophilia laboratory for genetic analysis. PSBC will then send a clinical report summarizing the test results to the HTC where the test was done. The patient's treating physician will then share the screening test results privately with his or her patient. This report will be stored in the individual's HTC record and in PSBC's secure laboratory information system. The clinical report will not be shared with insurers, employers or other parties. It will be up to patients whether they want to share the report with others, including family members. The program will adhere to best practices, and all state and federal laws designed to protect the privacy of patients, including the Health Insurance Portability and Accountability Act (HIPAA) and the 2008 Genetic Information Nondiscrimination Act (GINA).

Furthering Scientific Research for Future Generations

In addition to receiving results that could improve the management of their hemophilia, participants will have the option to simultaneously support scientific research by making their de-identified genetic data and samples available to researchers. At the time of the test, patients will be asked to provide consent to allow their data to be entered into the ATHNdataset, a secure community resource that is now supported by more than 130 HTCs. Patients can also consent to have their blood sample and DNA stored in a research repository at PSBC. MASAC recommends that individuals "strongly consider agreeing to have their de-identified mutation results added to the ATHNdataset" to further research and scientific understanding of the relationships between genotypes and clinical characteristics, called phenotypes.

In the future, scientists and researchers at academic institutions or drug discovery companies may apply for access to the data or samples through ATHN to support scientifically sound-research projects. ATHN's review committee will screen these applications to determine the feasibility and scientific validity of each project. No organization, including Biogen Idec Hemophilia, will be given preferential access to the data.

Further, neither ATHN nor researchers will ever have access to patient names or any other information that could be used to identify an individual, or his or her family. "The patient's identity will remain strictly confidential. Data and samples will be labeled only with a code number," says Diane Aschman, MS, president and CEO of ATHN.

Although individuals who do not wish to contribute their data or samples for research can still be genotyped, the hope is that most patients will consent to their data and blood sample storage, knowing it could help future generations of people with hemophilia. A list of approved research projects and the studies conducted using the research will be made available to the public.

"This is an opportunity to pool the unique information that each of us possesses to advance the scientific understanding of hemophilia," Bias says.

This article was taken from *HEMAWAKExpress,* April 2013, an online publication of the National Hemophilia Foundation.

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continued from page 1

PENNSYLVANIA AND DELAWARE HEALTH INSURANCE EXCHANGES

The Patient Protection and Affordable Care Act (the ACA) mandates that health insurance exchanges will begin operating in all states by 2014.

Health insurance exchanges are state-based competitive marketplaces where individuals and small businesses will be able to purchase affordable, private health insurance and have the same insurance choices as members of Congress.

The ACA provides a general framework for an "essential benefits package" of health care coverage that insurers must provide to people who obtain coverage through the exchanges. When the ACA is fully implemented in 2014, each state must offer policies providing at least 10 basic elements of health coverage.

Pennsylvania has announced that it will operate a "federally-facilitated" health insurance exchange beginning in 2014. We are not certain, at this time, if that model will adequately cover the needs of patients with bleeding disorders. Right now, we have many more questions than answers.

Delaware has announced that it will operate a state-federal partnership exchange and that looks a bit better because the state has added specific, clarifying wording (at the Chapter's request) regarding what benefits a DE health insurer must provide to people with bleeding disorders.

We believe that people with hemophilia and related bleeding disorders will look to the state health insurance exchanges beginning in 2014 for affordable health insurance that will cover their health needs. We are concerned that the coverage provided by participating insurers, particularly in Pennsylvania, may not adequately cover life-sustaining medicine and treatment.

Example: People with bleeding disorders need access to specialists (and sub-specialists) and appropriate sites of service (designated hemophilia programs) that are critical to the management of their disorders. Most specialists in hematology treat patients with more common blood-related conditions and have limited or no experience treating patients with hemophilia or related bleeding disorders. Access to a hematologist isn't enough. People with hemophilia and vonWillebrand Disease need access to sub-specialists within the area hemophilia programs, as these hematologists are identified experts in the treatment of patients with bleeding disorders.

Delaware has specific requirements in their state insurance exchange model stating that people covered by DE insurers will have open access to designated hemophilia programs and all brands of factor concentrates with no restrictions. Additionally, they have choices in pharmacy providers. We don't have the opportunity to provide language for the PA exchange, as it is a federally-facilitated model.

Another Example: People with bleeding disorders need access to all brands of factor concentrate, as there are no generics or therapeutic equivalents. Preferred formularies and other restrictions on factor choice place a person with hemophilia at serious risk. The decision about which factor concentrate is indicated for a patient must be made by the patient and treating physician, not the insurer, as factor concentrates are biologics and don't necessarily work the same for every patient.

HOW YOU CAN HELP

You can speak with legislators in Pennsylvania or Delaware; make them aware that the needs of people with bleeding disorders may not be addressed by their state's health insurance exchange, especially with the model Pennsylvania has chosen. Tell them that a clear process is needed regarding how appeals will be handled, and ask about how their state's exchange will be monitored and by what agency.

As we move closer to 2014, we look forward to getting some answers to the many questions we have regarding state health insurance exchanges. We promise to stay actively involved as an organization working with other health-related agencies to ensure that people with bleeding disorders are able to obtain affordable health insurance that actually pays for what they need. Stay tuned!

MEDICAID EXPANSION INDIVIDUAL STATES MAKE THE DETERMINATION

By Kadesha Thomas Smith and Marla Feinstein

Tetra Images/Glow Images

Medicaid has long been regarded as the safety-net health insurance program for low-income individuals and families, seniors and those with disabilities. As the nation's largest public health insurance program, it covers roughly 60 million people and is funded by federal and state dollars. The percentage of federal vs. state funding varies by state.

When the Patient Protection and Affordable Care Act (ACA) was signed into law in March 2010, it included a provision mandating all states to expand their existing Medicaid programs to include all US citizens up to age 65 with incomes below 138% of the federal poverty level, which is $14,856 per year for an individual or $30,675 for a family of four. This mandate was intended to expand eligibility primarily to childless adults, a population that does not qualify for coverage in most states. Currently, Medicaid covers people based on the state's income eligibility criteria.

In June 2012, the US Supreme Court ruled that states cannot be mandated to expand their Medicaid programs. However, states that choose to expand will receive additional federal funding to support new enrollees.

Starting in January 2014, members of the bleeding disorders community whose incomes were previously considered too high for Medicaid may be eligible. "Expanding Medicaid could potentially allow more vulnerable members of the population to participate, because eligibility will not be linked solely to disability status," says Michelle Rice, director of public policy for the National Hemophilia Foundation (NHF).

After age 18, childless adults are too old to qualify for the state's children's health insurance programs for low-income families. To remain on Medicaid, they must meet the state's criteria for disability. "Meeting a state's definition of disability is not always easy, and often varies from one instance to another," says Rice. "Medicaid expansion has the potential to prevent individuals from falling through the cracks."

As of March 2013, 25 states plus the District of Columbia planned to expand their Medicaid programs. Two others are leaning toward it, according to The Advisory Board Company, a healthcare research and consulting firm. Fourteen states have chosen not to expand coverage, and the rest are undecided. The federal government has stated it will finance a majority of the cost of expansion, including 100% of the costs in 2014–16 for individuals "newly eligible" (not previously eligible in their state). Beginning in 2016 this amount will be reduced yearly, ultimately ending at 90% by 2020.

Expanding Medicaid would allow more people with bleeding disorders to access coverage. There are clear differences in healthcare patterns between people with the same illnesses," says Rachel Garfield, PhD, senior researcher and associate director at the Kaiser Family Foundation's Commission on Medicaid and the Uninsured. "People with Medicaid are more likely to see a doctor, less likely to report problems," she says. "Coverage makes a difference."

NHF's public policy team often receives calls from individuals who either forgo treatment or use the emergency room as a primary provider, due to their inability to access healthcare coverage. Neither situation is recommended or ideal.

However, some Republican governors argue that simply expanding Medicaid without major Medicaid reform may not improve access to care and may make it even more difficult for states to provide adequate care. "Expansion without reform is not responsible and would bust the state budgets," states a letter sent to President Barack Obama by GOP governors Bob McDonnell of Virginia and Bobby Jindal of Louisiana.

"The money piece is significant in certain states," says Amy Lischko, DSc, associate professor of public health and community medicine at Tufts University School of Medicine in Boston. Healthcare already competes with other priorities for state funding, including education and public works. "Even though the federal government is paying most of the bill, many states are strapped for funding following the recession."

Throughout 2013, states will be weighing the options and making a decision about expanding their Medicaid programs. Rice foresees some of the opposing states changing their decisions. "States will be facing pressure not only from patient populations, but also from hospitals to expand," she says. Those that do not expand Medicaid will see costs rise elsewhere, Rice warns. "The care people do receive will be classified as uncompensated, which often makes care less affordable for everyone."

People with bleeding disorders should keep a close eye on these changes. NHF's public policy team will continue to keep you informed. Look for updates posted on NHF's website: www.hemophilia.org.

This article was taken from ***HEMAWAREExpress,*** April 2013, an online publication of the National Hemophilia Foundation.

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. These branches meet informally, in private homes, for social events and support. There is no charge for being 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