

INSURANCE AND HEALTHCARE OUTLOOK FOR 2012

Healthcare costs continue to increase faster than inflation

By David Linney | 02.07.2012

The US healthcare system is challenged by high costs during this tough economic period. Decisions about how to rein in these costs will need to be made by insurers, employers, states and the federal government. It's important to understand how they will affect people with bleeding disorders.



Healthcare costs continue to increase faster than inflation. Spending for specialty drugs, which include factor products, increased 19.6% in 2010, according to Express Scripts' 2010 Drug Trend Report. For a family of four with a preferred provider plan (PPO) in 2011, total insurance premium and out-of-pocket costs were \$19,393, a 7.3% increase over the previous year, according to the Milliman Medical Index. This index tracks healthcare costs annually using industry data and a survey of employers. Of the \$19,393, the employer paid \$11,385 for premiums, while the employee paid \$8,008 (\$4,728 for premiums and \$3,289 in out-of-pocket costs).

The National Hemophilia Foundation's (NHF's) advocacy team is keeping on top of these changes and is in frequent contact with congressional staff in Washington, DC. It is important that you continue to share information about any differences in coverage you encounter with your Hemophilia Treatment Center, or your access to factor products and home care companies.

[Steps for Living: Health Insurance]

CHALLENGES TO HEALTHCARE REFORM

The new federal healthcare reform law, known as the Affordable Care Act (ACA), is facing legal challenges. The law provides insurance protections, provisions to control healthcare costs and insurance purchase options for individuals and small employers (through insurance exchanges beginning in 2014). However, the constitutionality of the law is being challenged in several states. Opponents take issue with the provision requiring all individuals to purchase insurance, set to take effect in 2014.

Challenges have gone all the way to the US Supreme Court. If the high court determines the law is unconstitutional (decision should be reached by June 2012), it will probably focus on only part of the law, likely involving the insurance requirement or "individual mandate," not the entire law. The portions of the law that eliminate lifetime and annual limits, provide increased dependent coverage and limit pre-existing condition exclusions would probably remain in effect.

INSURANCE COST CONTROLS

Medicaid, Medicare, commercial health insurance providers and employers are trying to control rising healthcare costs by restricting insurance eligibility, reducing reimbursement, reducing benefits and increasing patient out-of-pocket costs.

These cost control measures come at a time of economic instability, which increases the potential that their number and level will be increased and put in place sooner. The uncertainty of the status of new healthcare reform makes this scenario even more complicated.

IMPACT ON PATIENTS WITH BLEEDING DISORDERS

Health insurance premium costs and out-of-pocket costs keep increasing. For individuals with bleeding disorders, many of whom reach their out-of-pocket limits every year, higher out-of-pocket costs mean an even greater budget drain.

A big unknown for individuals with bleeding disorders is the extent to which insurers will manage factor products and factor product providers—the homecare companies. Extra pressure to manage factor product costs will come from a number of new recombinant and longer-lasting products scheduled to enter the marketplace in the next few years.

continued on page 5



National Hemophilia Foundation

Delaware Valley Chapter

THE WINNING SPIRIT

SPRING/SUMMER 2012

VOLUME 19 #2 NEWSLETTER

NATIONAL HEMOPHILIA FOUNDATION

DELAWARE VALLEY CHAPTER

IN THIS ISSUE

- 2 – From the Executive Director
- 3 – Chapter Happenings
- 4 – Chapter Calendar
- 5 – Educate School Staff On Your Child's Needs By Laura Putre
- 6 – Shared Perspectives: Ann Rogers and Me by Elena Bostick
- 7 – Investigators Publish Two Studies Using UDC Data
- 7 – Simplified Insurance Forms Will Help Consumers
- 8 – Annual Meeting of the Region III Federally-Funded Hemophilia Treatment Centers by Hal Muschek
- 8 – Chapter Squawk Box
- 8 – DVC Support Network



ALERT!

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!

**National Hemophilia
Foundation
DELAWARE VALLEY
CHAPTER**

14 E. Sixth Street, First Floor
Lansdale, PA 19446
Phone: (215) 393-3611
Fax: (215) 393-9419
Web: www.hemophiliasupport.org

Christine Rowe, Executive Director
Kim Bayer, Administrative
Coordinator
Veronica Connelly, Administrative
Assistant

Board of Directors

Thomas D. Galvin, President
William L. Widerman, Vice President
Andrew B. Serrill, Treasurer
Cheryl A. Littig, Secretary

Board Members

Leonard Azzarano
Stephen Clowery
Patricia Felthaus
Nanette Germain
George Levy, HPPS President
Christopher Marozzi
Bob Sawyer
Kathleen Sell
Jonathan Worthington
Noel A. Fleming, *Esquire*
Legal Counsel

The *Winning Spirit* is a publication of the National Hemophilia Foundation, Delaware Valley Chapter. The contents of this newsletter may be reproduced freely, but please attribute the source. The material in this newsletter is provided for your general information only. The Delaware Valley Chapter does not give medical advice or engage in the practice of medicine. DVC under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local Treatment Center before pursuing any course of treatment.

Graphic Artist: www.chaley.com

We gratefully acknowledge the pledge of support from the following manufacturers for 2012.

Baxter Bioscience Recombinate Feiba NF Bebulin VH Advate Bayer Corporation Kogenate FS Koate-DVI	CSL Behring Monoclote-P Mononine Helixate FS Humate-P Stimate Novo Nordisk NovoSeven® RT Pfizer BeneFix™ Xyntha
---	--

FROM THE EXECUTIVE DIRECTOR

Each spring, we introduce our readers to the HPPS participating companies for the coming year!! Each of these companies provides pharmacy and home supportive services to local patients affected by bleeding disorders and has qualified as a 2012 participating company. Each company meets the very high standards of service set by Hemophilia Patient and Program Support, Inc (HPPS).

2012-2013 HPPS PARTICIPATING COMPANIES



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 and events throughout the year.

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!!

With this issue of *The Winning Spirit*, I leave my position as Executive Director of the Delaware Valley Chapter. It has been my privilege to be a part of such a great organization, made up of many, many wonderful and generous people. Your support to me and to the Chapter has been an inspiration. During my years here, I have witnessed some incredible advances in patient care, recombinant factor therapies (with longer-acting factor products coming very soon), the evolution of comprehensive care, homecare pharmacies providing supportive services to patients and now two generations of children who are healthy and active. And...gene therapy is bringing the promise of a cure for hemophilia, closer than ever before. Thank you for being such a big part of my life for so long. I know that you will support Christine Rowe in her new position as Executive Director of the Delaware Valley Chapter beginning July 1, 2012. I will hold each of you in my heart. My personal email is: annrogers911@comcast.net. Please stay in touch with me.

Thank you for so many wonderful years at the DVC!
Ann Rogers

Winning Spirit Newsletter GOING GREEN!!!

If you would like to receive your *Winning Spirit* via email (rather than through the mail), contact the Delaware Valley Chapter (215-393-3611) 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. 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!!

Call the DVC office (215-393-3611) for more information or to register for an event

BOWLING FOR FUN, FEBRUARY 25, 2012



Supporters and friends joined us at Thunderbird Lanes in Northeast Philadelphia for an afternoon of family fun to help us strike out bleeding disorders. What a great way to spend a winter afternoon with family and friends from the DVC! A special thank you to the Felthaus and Littig families for organizing the event.

ANNUAL FASHION SHOW & LUNCHEON, APRIL 14, 2012

The Annual Fashion Show and Luncheon was held this year at Cedarbrook Country Club in Blue Bell! The ladies enjoyed a beautiful spring day and the latest fashions from Old Navy, Banana Republic, Bowties Style and Annmarie Capasso dresses. A special thank you to all the ladies who volunteered their time to model the beautiful clothes. There was a waiting list for models this year so be sure to get your name in early for the 2013 show. Thank you to Nanette Germain, the event chairperson and the ladies committee for organizing this wonderful event!



WOMEN'S VWD RETREAT ON THE HILL, APRIL 27, 28 AND 29, 2012

Over 40 women enjoyed a weekend of education and relaxation at the Women's VWD Retreat held at the ACE Conference Center. The women enjoyed a weekend packed with information on VWD and had the opportunity to network with other women who are affected. Thank you to all of our guest speakers who helped make this event a success. A special thank you to our sponsor CSL Behring for making this weekend possible.

ANNUAL FAMILY DINNER, MAY 8, 2012

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 focused on a research update by Dr. Denise Sabatino, titled *Where is the Cure?* and a presentation made by Ann Rogers saluted *3 Women & 8 Men* who have contributed immensely to the work of the Chapter over the last three decades. The families said goodbye to Ann, who will be leaving her position as Executive Director on June 30th. It was an evening to remember!

BROAD STREET RERUN, MAY 14, 2012



WOW!! What a fantastic time! Over 700 runners and 150 kids hit the streets of Lansdale to participate in the 1/2 mile kid run and 5 mile run. This year we were so excited to have the Phillie Phanatic on hand to give the runners and kids a high five as they ran across the finish line. 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!!

CARLINO'S GOLF OUTING, JUNE 4, 2012



Sponsored by Carlino's Foods in Ardmore, PA, this was one of the nicest events of the year! This event was held once again at the Edgmont Country Club in Edgmont, PA. A big thank you to Carlino's Specialty Foods, Inc. in Ardmore, PA for sponsoring this annual event and a special thank you to owners, Laura and Pat Carlino and their very generous friends Kathy and John DiMichele for making this day possible! A big thank you to Pfizer for their sponsorship of this event!



BARBECUE COOK-OFF & HORSESHOES FOR HEMOPHILIA, JUNE 9, 2012

Over 25 teams competed from four different states for the best in ribs, chicken and chef's choice! What a delicious day it was! Teams also competed in the horseshoe tournament to be crowned the best ringer! Special thanks to Tom Rowe for organizing and serving some of the best food!

2012

Chapter Calendar

Call the DVC office (215-393-3611) for detailed information about the events listed here.

– June –

4 Carlino's Golf

9 Barbecue Cookoff & Horseshoes for Hemophilia

– August –

2-7 Double H Camp

4 Patient Information Program, Hershey

11 Home Run Derby

26 Perk Up Half Marathon

– September –

21-23 Family Camp

18 DVC Golf Classic

29 Patient Information Night

– October –

6 DVC Annual Walk/Run!

14 DVC Lancaster Walk/Run

19 Fall Gala!

26 Patient Information Night

– November –

8-10 NHF Annual Meeting: Orlando

17 Patient Information Night, Reading

– December –

1 Holiday Party

Patient Information Nights

Check on session titles by visiting the website at hemophiliasupport.org or calling the DVC office.

Patient Information Program "Living Well & Managing Costs" Hershey Lodge **August 4, 2012**

Patient Information Night Plymouth Meeting **September 29, 2012**

Patient Information Night King of Prussia **October 26, 2012**

Patient Information Night "Partnering with Your School" Reading **November 17, 2012**

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 hemophilia@navpoint.com

ALL DAY EDUCATION PROGRAM, HERSHEY LODGE, SATURDAY, JUNE 30, 2012!

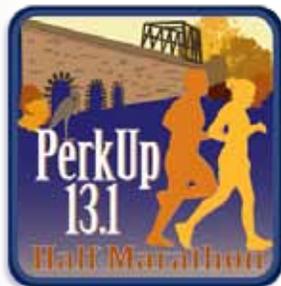
Living Well with a Bleeding Disorder & Managing the Costs. Childcare will be provided. Two wonderful sessions (lunch included) at the beautiful Hershey Lodge in Hershey, PA.

HOME RUN DERBY, SATURDAY, AUGUST 11, 2012 HATFIELD

Take me out to the ballgame! Register for the Home Run Derby and receive a t-shirt, hot dog, drink and a chance to win a trophy and Phillies Tickets. Visit www.hemophiliasupport.org for rules and registration.



THE PERK UP 1/2 MARATHON (THAT IS 13.1 MILES OF RUNNING FOR THE NON-RUNNING CROWD), SATURDAY, AUGUST 25 & SUNDAY, AUGUST 26, 2012!



Save the date as this event is going to need all hands on deck!! The DVC has partnered with the Upper Perkiomen Valley Chamber of Commerce for the Annual Perk Up 1/2 Marathon. The event will start and end at the exclusive Perkiomen School situated in the beautiful Upper Perkiomen Valley. This quiet corner of Montgomery County, Pennsylvania has exceptional natural beauty with rolling hills and flowing waters. The course is beautiful! Not up for the 13.1 mile running challenge? Sign up to be a volunteer! For more information, go to www.perkuphalfmarathon.com or call Christine Rowe @ the DVC (215-393-3611) or email to: christiner@hemophiliasupport.org.

DVC GOLF CLASSIC, TUESDAY, SEPTEMBER 18, 2012

Sponsored by CSL Behring, this event will be held at Rivercrest Country Club located in Phoenixville, PA. Dust off those golf shoes and join us for this fabulous day! FORE!

FAMILY CAMP, CAMP KWEBEC---NEW LOCATION---SEPTEMBER 21-23, 2012

We are going to a new camp this year! Camp Kwebec is located in Schwenksville, PA just a few miles from our old camp and we will have the entire camp to ourselves for the whole weekend. The weekend is for children with hemophilia or VWD and their immediate families and adult patients and their immediate families. This is a great opportunity to meet other families that are affected by bleeding disorders. Join us for a weekend of fun activities!

DVC 5K RUN & WALK * 2 LOCATIONS TO CHOOSE FROM OR DO BOTH! *****

5k Run/Walk and 1/2 Mile Kid Run, Saturday October 6, 2012 Collegeville

Join all of us on Saturday, October 6th at the 3rd Annual 5k Run & Walk as we walk or run and raise funds to help find a cure for hemophilia and von Willebrand Disease. All funds raised will stay local and benefit the Delaware Valley Chapter of the National Hemophilia Foundation. Become a fundraiser today and form a team! Visit www.active.com/donate/dvcwalk We have awesome team fundraising prizes! Join today!



5k Run/Walk and 1/2 Mile Kid Run, Sunday, October 14, 2012 Lancaster

One week after the Collegeville location you can join us in Lancaster at The Park City Mall. What could be better than a family fun day followed by a shopping trip to Lancaster County! This is the first year for this event and will take place on the grounds of Park City Center right outside the shopping mall. Visit www.active.com/donate/dvcwalklancaster to form a team, register for the event or to make a donation to this location. Lace up your sneakers and get ready to run, walk and shop!



FALL GALA, FRIDAY, OCTOBER 19, 2012

Join us for a wonderful evening at the Hilton Hotel, City Line Avenue, Philadelphia, PA. This is a premier event for the Chapter and you will not want to miss it. Purchase tickets by calling the office or online at www.hemophiliasupport.org.

Insurance management of factor products can include prescription prior authorization requirements; prescription case management; restricted formularies (in which some factor products in a class of factor products are not covered); different drug tiers (or levels) of coverage for different factor products; and step therapy, in which a lower-priced factor product is required to be used and determined to be ineffective before a more expensive product can be prescribed.

Insurance management of factor product providers will focus on how many providers an insurer will approve and the price it will pay for each factor product. In the future, it is likely that insurers will approve fewer factor product providers, which limits patient choice, to control costs and maximize efficiencies.

“Understanding and evaluating your health plan options can be a difficult and tedious process. However, for those affected by a chronic condition, the decision about which health plan is most appropriate for your needs may be one of the most important decisions you make,” says Val Bias, NHF’s CEO. NHF has developed a Personal Health Insurance Toolkit to help guide you through the evaluation process. For a copy, go to www.hemophilia.org and click on the Health Plan Comparison Guide link in the Helping Consumers box.

Previous article taken from HemAware.org, an online publication of the National Hemophilia Foundation.

EDUCATE SCHOOL STAFF ON YOUR CHILD’S NEEDS

By Laura Putre | 05.03.2012

When your child has hemophilia [or VWD], it’s important to work closely with his/her school to educate key staff members about his [or her] health condition and to put an emergency plan in place with the school nurse—if there is one.

Doing so is even more essential now because fewer than half of U.S. public schools have a full-time registered nurse on staff, according to the National Association of School Nurses (NASN). Seventy-five percent of schools employ either a part-time or full-time registered nurse.

“Parents should take the lead,” says Kim Schafer, RN, BSN, the pediatric hemophilia nurse coordinator at the Hemophilia Treatment Center at University of California-Davis. “They should really make contact with the school early to begin education about the bleeding disorder. They should let the school know that they’re open to communication through e-mails and phone calls.”

A school plan should include phone numbers for parents and the local Hemophilia Treatment Center (HTC), as well as specific directions on what to do in case of an emergency, Schafer says. It should also explain how to recognize mild, moderate and severe bleeds, and direct school staff to contact the HTC—and a parent—if the child is already bleeding.

Each school year, parents should request the proper medication forms from the school and make sure the documents are signed by the treating physician, Schafer recommends. That way, she says, the school can keep the medications on site, either in a locked box or a refrigerator.

It’s also a good idea to request a meeting with the school nurse and office staff, teachers and playground workers before the school year begins. Anyone who might handle small injuries and might have questions should be included, Schafer says.

Schafer also suggests inviting the HTC nurse and social worker to attend the meeting. Talking things through may help ease the nerves of the school administration and staff, she says. “A lot of times, I make visits to the school, especially for the younger kids just starting in the school system, to get everything established,” Schafer says.

Also encourage your child to participate in the meeting. This helps the school staff recognize your child and remember what his/her needs are, says Schafer. And it’s wise to start

educating a child early to report bleeds to the teacher or other school staff right away.

“Parents can play a huge role in teaching their children to communicate when they are hurting,” says Schafer. It’s vital that the child either self-infuses or has an adult do it as soon as possible, she says.

Jeanette Cesta, mother of three school-age children who have moderate to severe von Willebrand disease, often includes them in meetings with the school nurse. “Have your kids come and explain as much as they can,” she advises. “When the kids are in school, you’re not going to be there.”

Cesta suggests scheduling a time to meet before the school year starts. “I always try to go in at the end of the [previous] school year and find out if school staff will be available over the summer to talk to,” she says.

Sometimes, though, even the best-laid plans can fall apart. Cesta recalls one time when her daughter, then 10, got hit with a basketball in gym class, and the substitute teacher refused to let her go to the nurse’s office. Afraid to push further, her daughter waited a half hour until class ended to go to the nurse’s office. Cesta followed up with the school after the incident. Together they came up with a plan to make students’ medical records available to substitute teachers if the parents agreed in writing.

If your child’s school doesn’t employ a registered nurse, you need to have a different plan. “Parents should always ask who’s in the health room,” advises NASN executive director Donna Mazyck, MS, RN, who has a National School Nurse Certification. “You want to know for sure because it may be an unlicensed assistant—for example, a health aide—who’s in that school every day.”

Mazyck adds that if a school doesn’t employ a registered nurse, it is still required to provide healthcare services for students who qualify under the Individuals with Disabilities Education Act, or Section 504 of the federal Rehabilitation Act. If health services are required, the school must work with a registered nurse to develop an individualized healthcare plan.



SHARED PERSPECTIVES: ANN ROGERS AND ME

by Elena Bostick, Executive Director, Hemophilia Association of New Jersey

We were girls in our 20's when we became involved with our hemophilia organizations: Ann because her son had hemophilia and I because the Association was close to home. Little did we know the path before us would lead to such a driving force. It would occupy the better part of our lives going forward. With much to do, Ann and I set out to make a difference. Back then, so little was in place in terms of the provision of services to persons with hemophilia. Even within our own respective organizations, committee structure was deficient, strategic planning was non-existent, and fund raising efforts raised just enough to cover the few services we were providing. Looking back at it all, we were bound to become stars. From that entry level, we had nowhere to go but up.

I wish I could tell you it was an easy road, but it wasn't. The tragedy of the AIDS crisis set the tone for our tenacity. I wish I could tell you we accomplished everything that was needed, but we didn't. The exercise we learned the hard way, was to continuously evaluate the nature of a threat, and evaluate its potential impact on hemophilia. Once this exercise was mastered, it guided us into whatever action would be required.

Ann and I were in agreement all those years ago that we must not throw the baby out with the bathwater. The challenge for us was to preserve policies and programs that worked, try to make them work better, and to be relentless about anything that posed a threat. This meant monitoring activity that might affect us, initiating action to promote hemophilia interests and block action viewed as detrimental. The Pennsylvania Medicaid issue of a few years ago is a perfect example of this. It meant being informed, present, engaged and most of all RELENTLESS.

As I was writing this, and even now as I present it, it is difficult for me not to chuckle. The word "relentless" defines Ann Rogers! I have often heard her refer to me as her cheerleader. The truth of the matter is, Ann Rogers does not now, nor has she ever, needed a cheerleader. So regardless of the occasion, our function was to channel all of our energy into educating those that mattered, and try to sound calm and reasonable while we were doing it. Very often it went something like this:

1. Clotting factor concentrates are not recreational drugs that require higher and higher doses to satisfy the user, although some insurers would have you think so.
2. Factor replacement therapy is not an option for the person with hemophilia. It is an absolute need.
3. Clotting factors are not therapeutically equivalent and therefore, not necessarily interchangeable.
4. Restrictions on product access are not acceptable.
5. Interference in clinical decisions made by a physician in consultation with a patient is not acceptable.

6. Jeopardizing medical outcomes in an attempt to contain costs is simply not acceptable.

These were statements we utilized repeatedly over the course of our thirty years and, unfortunately, these are statements we are still using today. It is the nature of our healthcare systems, both new and old.

So what does that tell us? It tells us that **ADVOCACY** is the most important provision of organizations like ours. It is the continuous repetition of the services and products required by those with bleeding disorders to those that can make it happen, that is critical. It means having a place at the table when decisions are made about standards of medical care that affect our lives.

Make no mistake, the bureaucrats in Harrisburg, as well as those in Trenton know who we are. They know our names and they recognize our faces. They may try to hide when they see us coming, but we've learned how to find them. They know that we continue to fight for our right to quality healthcare. That's the **ADVOCACY** we have cultivated for our organizations and that is the advocacy that must continue until a cure is found. Ann and I have also learned that advocacy means differentiating hemophilia from the rest, because many Americans have some chronic conditions that are not necessarily impairing, and while drug therapies may be prescribed, they often do not require extraordinary care. However, there is a smaller group of individuals whose lives and medical outcomes are dependent upon access to treatments deemed necessary and appropriate by the treating physicians. Across the board reforms ignore the challenges posed by individuals with the greatest need, and at the greatest risk. Our message has been and must always be: Hemophilia is different--hemophilia is different--hemophilia is different.

I know there are legislators in Harrisburg that flail their arms and shake their heads when they hear Ann Rogers is on the phone. Can you picture it? Thirty years ago, we were mortified. We thought "Gee, he must not like me." Today, it is a very different response. That kind of stuff no longer discourages us. It simply tells us what is needed--to call again tomorrow, and the next day, and again the next. Whatever it has taken to get things done, is what we have done--my buddy and me.

So Ann, my dear friend and kindred spirit, the occasion of your retirement, although melancholy is some ways, must give you a tremendous sense of accomplishment and reward. You have touched the lives of so many and made them so much better. You gave them "hell" in Harrisburg and in Washington, DC, and.....you've put the Delaware Valley Chapter of the National Hemophilia Foundation on the map! Congratulations.

continued from page 5

EDUCATE SCHOOL STAFF ON YOUR CHILD'S NEEDS

Still, sometimes instructions need to be clarified or reinforced. Schafer once had a student who went to the school office complaining of a muscle bleed. When the staff couldn't reach the child's mother, they panicked and called an ambulance. The child made an unnecessary visit to the emergency room.

When something goes awry, Schafer says, it's best to be direct without pointing fingers. Parents can say, "Things didn't quite work out as planned. Let's go back, look at the care plan and see if there is something different we need to do."

Previous article taken from HemAware.org, an online publication of the National Hemophilia Foundation.

INVESTIGATORS PUBLISH TWO STUDIES USING UDC DATA

A pair of studies in the December 2011 edition of the American Journal of Preventive Medicine highlighted some notable findings from data collected by the Centers for Disease Control and Prevention (CDC).

In the first study, "Insurance, Home Therapy, and Prophylaxis in U.S. Youth with Severe Hemophilia," the authors reviewed data from the CDC's Universal Data Collection (UDC) project, a voluntary surveillance system that relies on patient enrollment. The lead author of the study was Judith R. Baker, MHSA Department of Pediatric Hematology/Oncology, University of California Los Angeles.

Included in the study was a nationwide cohort of 3,380 boys and young men with severe hemophilia A or B, ages 2-20 years old, all of whom had received care at a federally funded hemophilia treatment center (HTC) between January 1, 2008, and December 31, 2010.

The results showed that 90% of patients used home therapy and 78% were on a prophylaxis treatment regimen. Only 2% were uninsured. Investigators found that those with health insurance were much more likely to be on prophylaxis (77%) vs. those who were uninsured (21%). The data also showed significant correlations between race, age, inhibitor status, and HTC use, home therapy use and prophylaxis.

"Youth with severe hemophilia who annually obtain care within the U.S. HTC network had a high level of health insurance, home therapy, and prophylaxis. Exploration of factors associated with insurance coverage and yearly

HTC utilization, and interventions to optimize home infusion and prophylaxis among youth of African-American and 'other' race/ethnic backgrounds are warranted," concluded Baker and her colleagues.

Investigators also drew on UDC data for the second study, "Physical Functioning in Boys with Hemophilia in the U.S." The lead author was Paul E. Monahan, MD, Department of Pediatrics, Hematology/Oncology, University of North Carolina at Chapel Hill. Researchers reviewed 15 potential predictors of poor physical functioning in boys with hemophilia A and B (up to 18 years of age) who had received care at an HTC between 1998 and 2008.

They found that several characteristics were associated with limitations of joint function, including increasing age, presence of joint bleeding and inhibitors. African-Americans were also independently associated with activity restrictions. In addition, obesity and medical coverage with Medicaid, as opposed to private health insurance, were independently associated with multiple poor outcomes.

"Interventions focused on eliminating inhibitors, improving outcomes for African-American children with hemophilia, and maintaining healthy body weight are warranted. In addition, strategies are needed to assure adequate insurance coverage for all people with hemophilia to eliminate economic barriers to optimal functional outcomes," the authors concluded.

Source: Obesity, Fitness & Wellness Week, January 7, 2012

SIMPLIFIED INSURANCE FORMS WILL HELP CONSUMERS

Documents that give an overview of insurance benefits and healthcare costs coming soon

By January W. Payne | 04.13.2012



Consumers will soon have access to simplified documents explaining insurance benefits and healthcare costs, thanks to a provision of the Affordable Care Act that takes effect later this year.

Starting September 23, 2012, health insurers will be required to provide two forms that explain important details of benefits and coverage. The National Association of Insurance Commissioners, an organization created and run by chief insurance regulators from all 50 states, developed the prototypes for the forms.

Until now, consumers often did not have enough information to make informed decisions about which health insurance plan to choose, says Ruthlyn Noel, senior manager of public policy at the National Hemophilia Foundation (NHF). "For the first time, consumers have a tool to serve as a guide in assessing health insurance plans for themselves and their families," she says. The availability of these new forms will give consumers the advantage of being able to sit down as a family, or as an individual, to compare coverage options and costs, Noel says.

The two forms—a Summary of Benefits and Coverage (SBC) and a uniform glossary of terms—will be provided

at key points in the insurance enrollment process, such as when applying for coverage or renewing your policy.

The SBC will describe key plan features, such as insurance benefits, cost-sharing provisions and coverage limitations and exceptions, according to HealthCare.gov, a consumer website run by the U.S. Department of Health and Human Services. It will also include "coverage examples," which will explain how much a plan will cover for two common scenarios—delivering a baby or managing type 2 diabetes.

The glossary will help consumers understand jargon often used in health plans. For example, it will define terms such as "out-of-network co-insurance" and "balance billing," reports HealthCare.gov, which will also house the glossary online.

A 2011 study by New York-based Consumers Union (CU) found that the forms helped improve consumers' understanding of the purpose and value of health insurance. They also made shopping for a health plan easier, according to an August 2011 CU news release.

"The success of health reform will depend to a large degree on making insurance options understandable to consumers and helping them to make informed choices," said James R. Knickman, president and CEO of the New York State Health Foundation, in the CU news release. He said the new forms will help fulfill those purposes.

continued on page 8

In addition, you should consider bleeding disorder-specific issues not addressed by these forms, Noel says. NHF's Health Plan Comparison Guide is a useful tool. It suggests asking such questions as:

- Is clotting factor covered by the plan? If so, is it a major medical or a pharmacy benefit?
- Do you have a choice of more than one pharmacy provider?
- Is your hemophilia treatment center in network?
- Do you need a referral to see a specialist?

The guide also suggests creating a "personal health experience" sheet that lists which health services you've used in the last year. For example, you can tally how

frequently you:

- Visited your primary physician
- Were seen by a specialist
- Visited your HTC
- Made a trip to an ER or urgent care center

But these are just some of the issues to keep in mind if you have a bleeding disorder and are considering health insurance options. Be sure to read the entire NHF Health Plan Comparison Guide (find it on www.hemophilia.org) before you choose a health plan.

Previous article taken from HemAware.org, an online publication of the National Hemophilia Foundation.

On April 19 and 20, 2012, I had the opportunity to attend the Annual Meeting of the Region III Federally-Funded Hemophilia Treatment Centers in Alexandria, VA. The five Chapters of the National Hemophilia Foundation also sent representatives. On day one, an overview of inherited platelet disorders was presented. Later, in the consumer breakout group, discussions focused on how to get teens and tweens more involved in local Chapter events and support groups, working with their treatment plans and taking more responsibility for their own care needs. Also discussed were ways to get them involved in state advocacy, legislative issues pertaining to them and navigating their own insurance. On day two, presentations were made on inhibitor management, joint and mobility issues, education and clinical research. There was also a presentation on healthcare reform and how it will impact people with bleeding disorders. Overall, this was a very informative meeting.

Hal Muschek, Chapter Volunteer

CHAPTER SQUAWK BOX

Many times throughout the year, readers write to the Chapter with questions. Here is a recent one and the answer!! Send us your questions!!

Question: Why doesn't the Delaware Valley Chapter give medical advice and tell us what treatments are the best and where to go for treatment? We are a family of a newly-diagnosed baby with a bleeding disorders. We need help!

Answer: The Delaware Valley Chapter is happy to help you in so many ways. In fact, helping patients, parents and families is the most important thing we do each day.

Although we can't provide medical advice or tell you what treatment is best for you or your child, we can help steer you in the right direction to get answers to your questions. There are seven wonderful hemophilia programs in our area that provide excellent care to children and adults with hemophilia and von Willebrand Disease. These programs specialize in the treatment of individuals with rare, bleeding disorders. Give us a call and we can help you find one of these "centers of excellence." They will be able to answer

your questions about care and products.

The Chapter also hosts many educational sessions throughout the year in different locations, providing excellent presenters on a wide range of topics of interest to affected patients and families. If you provide your complete contact information to the Chapter, we can make sure you are invited to these excellent sessions. We also have family events that provide an opportunity for you to meet other families who understand the challenges you have. These events are posted in our monthly e-news and on our Chapter website (www.hemophiliasupport.org). Email your information to hemophilia@navpoint.com.



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 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.

Delaware Branch
Gail & Luke Vannicola
302-378-1278

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