

PEN's Insurance Pulse

Inspiring Advocacy

Inside

- 2 Welcome**
- 3 Transitions**
Empower the Girl,
Empower the Woman
- 6 Ask the Expert**
Copoly Assistance Denied!
- 7 My Life**
Get Out of Jail Free—
This Time
- 8 Community Forum**
Future of the ACA
- 10 Tracks & Trends**



Murky Waters: Dealing with Uncertainty in Healthcare

Michael Bradley

Uncharted Waters

Uncertainty is a normal daily event for most of us. We wake up every morning not knowing what mood we'll be in, how bad the traffic will be, what the weather will be like, what work will have in store for us. Now, every day we also wonder what changes in healthcare will be in the news. We can be certain that the changing healthcare market will have some impact on our lives. Staying current with all the changes can be a full-time job, especially for people affected by a bleeding disorder.

It's vitally important that you stay on top of key healthcare issues, even if you find them confusing at times. But remember, you don't need to be an expert. You just need to stay informed, create a network of people and experts to talk with, and believe that you have a voice and can make a difference in your own healthcare.

continued on page 4



Welcome

PEN'S INSURANCE PULSE

Editor-In-Chief

Laureen A. Kelley

Contributing Writers

Michael Bradley

Wendy E. Owens

Michelle Rice

Ian Thomas

Senior Editor

Sara P. Evangelos

Science Editor

Paul Clement

Layout Designer

Tracy Brody

Publications Manager

Jessica O'Donnell

Manager, Projects & Production

Zoraida Rosado



Published by

LA Kelley Communications, Inc.

37-39 West Main Street, #8

Georgetown, MA 01833 USA

978-352-7657 • fax: 978-352-6254

info@kelleycom.com

www.kelleycom.com



It's hard to write an article about health insurance reform when you know that by the time you go to press, every policy, bill, and even the players will have changed! It's a risk we take as publishers.

And right now, many risks to health insurance threaten the hard-earned coverage and benefits we've achieved—and need—as people with chronic bleeding disorders. The Health Care Freedom Act (HCFA) was defeated in the Senate with a dramatic final vote. Had it passed, the Congressional Budget Office predicted that 22 million more people would be uninsured by 2026. This painted a dismal picture for healthcare in America, including much higher deductibles and a 26% reduction in Medicaid spending by 2026.

While the bill was being debated, and facing huge losses in benefits and coverage, the bleeding disorder community scrambled to action, and begged members to contact their senators. On Hemophilia Federation

of America's (HFA) Facebook page: "ACTION ALERT: Time is of the essence and we need YOU to call your Senators to ask for a NO vote on the 'Better Care Reconciliation Act!' Objective analysis of many of the provisions of this bill show that it will reduce coverage, increase costs, and put at risk thousands of those with bleeding disorders that rely on Medicaid! CALL YOUR SENATORS TODAY!"

This is the beauty of our community: powerful advocates with a proven track record of changing history in Washington. Our advocacy groups—National Hemophilia Foundation, HFA, your local chapter—need your participation and support more than ever. Even though the AHCA did not pass, its proponents will try again. Our community advocates can't safeguard our healthcare needs and rights without your voice and your action.

The facts you read in this issue of Pulse may have changed since we went to press. But remember, print material always highlights how much is at stake, and how we need to safeguard our hard-earned healthcare coverage gains. Because one thing never changes: we all must be involved in our own healthcare on a personal level, state level, and national level. At each level, you'll find great organizations to help you. So what can you do? Read. Call. Act!

Laurie

PEN's Insurance Pulse is a newsletter for families and patients affected by bleeding disorders. It is published by LA Kelley Communications, Inc., a worldwide provider of educational resources for the bleeding disorder community. Pulse focuses on insurance, coverage and reimbursement policies, trends, family profiles, and expert opinions.

PEN's Insurance Pulse respects the privacy of all readers and patients with bleeding disorders. Personal information (PI), including but not limited to names, addresses, phone numbers, and email addresses, is confidential and kept secure by the LA Kelley Communications editorial

staff. Pulse publishes information only with written consent. Full names will be used unless otherwise specified.

PEN's Insurance Pulse is solely sponsored by Shire. The views expressed by various contributors to Pulse do not necessarily reflect those of the editor, publisher, or corporate sponsor.

PEN's Insurance Pulse is in no way a substitute for medical care or personal insurance responsibility. Parents or patients who question a particular symptom or treatment should contact a qualified medical specialist. Parents or patients with personal insurance questions should contact their employer's

human resource department, Medicaid or Medicare caseworker, payer representative, or HTC social worker.

Articles may be reprinted from PEN's Insurance Pulse only with express written permission and with proper citation. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopy, recording, or any information storage and retrieval system, without written permission from the publisher.

Funding provided for PEN's Insurance Pulse with an unrestricted grant from Shire.



Empower the Girl, Empower the Woman

Wendy E. Owens

Let's talk about your daughter and whether she might be a carrier for a genetic mutation that causes hemophilia. According to National Hemophilia Foundation's (NHF) Steps for Living, there's a chance that a woman is a carrier if she is the mom, grandmother, or sister of a biological son, grandson, or brother with hemophilia; or the aunt, cousin, or niece of a male with hemophilia related through her mother. If your daughter fits any of these scenarios, NHF's Medical and Scientific Advisory Council (MASAC) recommends that she undergo genetic testing to determine her carrier status.

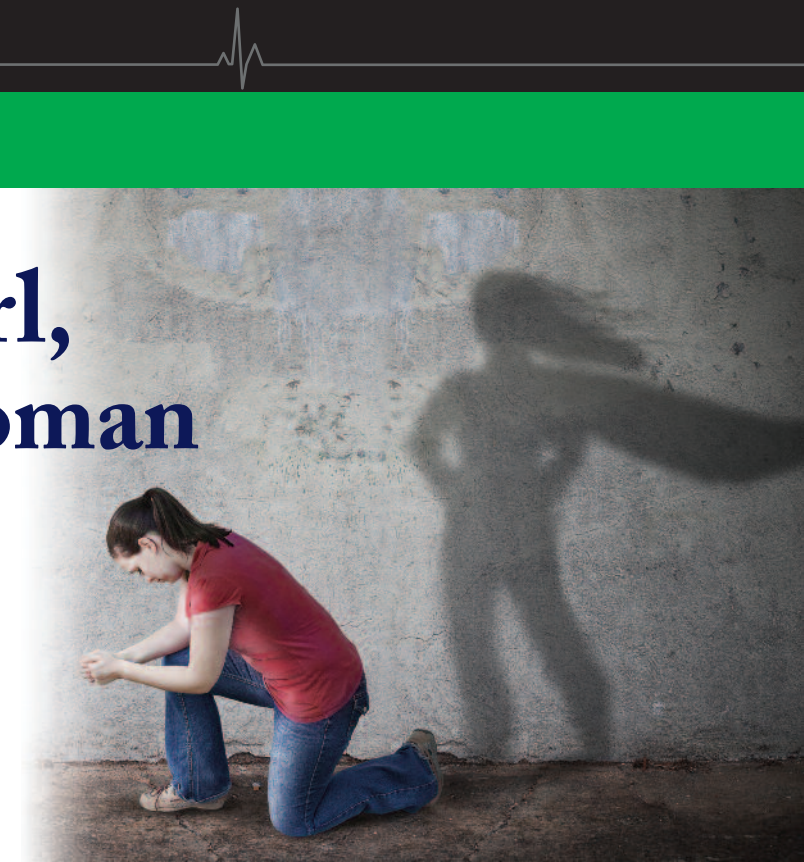
What Is Genetic Testing?

Though once in the realm of sci-fi novels, genetic testing is now mainstream. Genetic testing identifies changes in the normal structures of proteins, genes, and chromosomes. An integral part of genetic testing is the counseling that goes with it. Meg Bradbury, senior genetic counselor at GeneDx, Inc., describes genetic counseling as "the process of helping patients understand and adapt to medical, psychological, and familial implications of genetics contributing to disease."¹

Bradbury explains that genetic counseling breaks down into three parts: "interpretation of medical histories to assess the chance of disease occurrence or recurrence; education about inheritance, testing, management, prevention, resources, and research; and counseling from a genetic counselor to promote informed choices and adapt to the risk or condition."

Does Insurance Cover Testing?

Many large health insurance plans cover genetic testing when it's recommended by a doctor. In fact, \$5 billion annually is spent on genetic testing. Within the next ten years, this number could reach \$15 billion to \$25 billion.² "Often, genetic testing for hemophilia is a covered benefit because learning hemophilia carrier status can impact medical care," says Sumedha Ghate, genetic counselor at Hemophilia Outreach Center in Wisconsin. "When you are making decisions about whether or not to pursue



gene testing for carrier status and you have questions about insurance coverage, first talk to a genetic counselor. They have up-to-date information and can answer your questions."

Many insurance companies consider genetic testing medically necessary if a person is at risk for inheriting a disease or disorder. Aetna Inc., for example, offers policies that cover genetic testing for hemophilia A and B. Aetna considers genetic testing medically necessary if a patient "is at direct risk of inheriting the mutation in question and the result of the test will directly impact the treatment," among other reasons.³

The trouble is, insurance coverage for genetic testing is inconsistent among health insurance companies, and even within a single company's plans. For instance, Medica Health Plans covers single-gene testing for carrier status of heritable disorders when (1) testing is ordered by board-certified medical geneticist or genetic counselor; or (2) the patient has symptoms of or a family history of a genetic disorder.⁴ But while Medica covers genetic testing for hemophilia A, it doesn't cover the same testing for hemophilia B.

The Practical Impact of Testing

Your daughter has a right under the US and state constitutions to make certain reproductive choices, including having genetic testing.⁵ But there are pros and cons to genetic testing. It's essential to talk to your daughter about the risks of *not* being tested, given her chances of being a carrier, as well as the risks of being tested.

continued on page 14

1. Hemophilia Federation of America, <https://www.youtube.com/user/VoicesHFA> (accessed May 17, 2017). 2. Christina Farr, "If You Want Life Insurance, Think Twice Before Getting a Genetic Test," <https://www.fastcompany.com/3055710/if-you-want-life-insurance-think-twice-before-getting-genetic-testing> (April 6, 2016, accessed May 3, 2017). 3. "Genetic Testing," Aetna, http://www.aetna.com/cpb/medical/data/100_199/0140.html (accessed May 3, 2017). 4. Medica Coverage Policy, Genetic and Pharmacogenetic Testing (policy name), https://www.medica.com/-/media/documents/provider/coverage-policies/genetic_and_pharmacogenetic_testing_cp.pdf?1a=en (accessed May 31, 2017). 5. Institute of Medicine (US) Committee on Assessing Genetic Risks, Lori B. Andrews et al., eds., "Social, Legal, and Ethical Implications of Genetic Testing" (Washington, DC: National Academies Press, 1994), <https://www.ncbi.nlm.nih.gov/books/NBK236044/> (accessed May 31, 2017).

Murky Waters *from cover*

To make sure there's no uncertainty about *this* article, it will focus on the changing face of healthcare in the US, and on the importance of understanding your current healthcare situation, creating a plan of action, and then taking action to become a more informed healthcare consumer. Let's put this into a real-life situation, and see how staying informed can have a dramatic impact on your life by creating more certainty.

Adjusting Your Sails: Craig's Story

In the late fall of 2009, Craig, who has hemophilia, was looking forward to attending graduate school. What he was *not* looking forward to was the financial transition that this move would involve—not just paying for college, but finding affordable healthcare.

Craig was nearing his lifetime cap on his mother's insurance. When he'd hit that cap—the maximum amount his insurance would cover—he would no longer be covered. Craig remembers sitting with his mother at the kitchen table, insurance papers in one hand and a large calendar in the other, planning out exactly how much cap space he had left, how much medicine it would cover, and how long that medicine would last.

Craig knew he would need a new insurance plan that summer; insurance laws (rather than graduate program selection) would be one of the primary motivators in choosing a graduate school. He eventually chose a school in New York because he was guaranteed not to be disqualified for insurance due to his preexisting condition. Even then, Craig faced the painful truth that his student insurance would not cover his factor. He needed another plan. So he ended up buying additional private insurance that was part of a high-risk pool—to the tune of over \$1,200 a month. Craig's monthly income was just over \$1,300 a month. Luckily, he was able to get some financial assistance to help pay his monthly premiums.

In 2010, the Affordable Care Act (ACA) was passed. Craig was able to adjust his plan again, and he enrolled in one of the Health Insurance Marketplace plans. He was able to work with his insurance company to cut his premiums almost in half, to under \$700, with no meaningful change in coverage—an incredible boost for a struggling graduate student. Then, with the expanded Medicaid eligibility in 2014 in his state, Craig adjusted his plan once more, and was able to qualify for Medicaid. For the first time, his family was freed from the financial healthcare burden that had become a normal part of his life.

Becoming a Champion

Craig took advantage of these healthcare changes because he stayed informed. He was an advocate. Advocacy needs to be a basic part of life, especially when you're in the bleeding disorder community. But there are many different definitions and types of advocacy: grassroots, legislative, healthcare, insurance, self, family, professional, and legal advocacy. To simplify, instead of using the word "advocacy," I'll use the term *healthcare champion*. So, let's talk about what becoming your own healthcare champion means.

One definition of champion is "a person who fights or argues for a cause or on behalf of someone else." First, it's essential to become a champion for yourself, actively managing your own health. Second, you need to become a champion for your family, your friends, and your community. But you don't have to do it alone! There's nothing better than finding someone to walk beside you on your journey down the road of healthcare understanding.

We have all seen what's happening in the retail industry. Some of our favorite stores are closing, while others are cutting staff and making the shopping experience feel more like pumping gas at a self-serve station. It's so easy to shop online in the comfort of our homes, to cash checks by taking a cell-phone picture, and to talk to a gadget that will order stuff for us! We're becoming a self-serve society, and healthcare is rapidly moving in the same direction.

Self-directed, high deductible, health savings account (HSA), managed care, Health Insurance Marketplaces—these are all types of insurance plans that force us to make our own choices about healthcare. What should my deductible be? Is my doctor covered? Can I go to my hemophilia treatment center (HTC)? How do I choose the deductible that fits my current financial situation? How best to ask my doctor or nurse about alternative forms of treatment? These are just a few of the many questions we all need to answer.

I remember having a conversation with my mother a few years ago, when my dad was ill. I was concerned that he was getting different advice from each of his physicians, and I suggested that my mom discuss this with his healthcare team. She told me she couldn't challenge my dad's doctors—that they knew what was best. This got me thinking about how much healthcare has changed over the past several decades.

When my parents were young, many doctors made house calls and knew each patient personally. Flash forward two decades, to when I was young: now, doctors were much busier, but there was still that personal touch. Move ahead some more:

in today's world, we're lucky if we get more than 15 minutes of a doctor's time, if we meet with a doctor at all! This is why it's crucial to make the most of the time you have with your treatment professional, and to have a list of concerns and questions ready. Prioritize the questions you want to ask, and make sure you ask the most important ones first. Part of being a healthcare champion is being able to tell your story to your healthcare provider. Who knows you better than *you*?

In today's fast-paced, connected world, we can no longer assume that our clinical team has the time to really get to know each of us personally. Instead, it's up to us—the patients receiving the care—to educate ourselves and become our own healthcare champions. We can't all become experts on insurance, but we can make a plan to learn more about our own healthcare. If you live with a bleeding disorder, you're lucky to have a lot of information at your disposal—sometimes, it seems like too much—but knowing where to go, who to ask, and how to get educated can make life a lot easier.

Let's Take a Quiz!

Before you educate yourself about insurance and healthcare, you need to know what you don't know! Let's test your knowledge on current healthcare events. One more challenge: Put down your phone and close your computer so you can do this the old-fashioned way!

1. What is the common name for the Affordable Care Act, or ACA?
2. Name four areas of the ACA that have benefited the bleeding disorder community.
3. What is a Health Insurance Marketplace?
4. What percentage of people with hemophilia are covered under Medicaid? What about people with von Willebrand disease (VWD)?
5. Are there programs for people with bleeding disorders that can provide assistance with insurance copayments and deductibles?
6. Do the Democrats and Republicans agree on healthcare reform? Did they agree on the ACA?

Answers on page 15!



Making It Crystal Clear: Basic Insurance Terms

How did you do on the quiz? It's time to learn some basic insurance facts, so you can become your own champion. First, what were some of the key insurance issues for the bleeding disorder community before the ACA?

Lifetime Caps: In many cases, patients would exhaust their health insurance benefits because they had reached the maximum amount, or “cap,” that their insurance company would pay.

Limited Medicaid Availability: Originally, Medicaid was created for children and for women with families. In most states, it was very difficult for a male adult with hemophilia to enroll.

Preexisting Conditions: When patients changed insurance companies, many private insurers would not cover their health conditions that had existed for a defined amount of time. All bleeding disorders would fall into this category.

Coverage for Young Adults: Before the ACA, many young adults were dropped from their parents' policies after they reached age 18, or possibly 23 if they were enrolled in school.

High-Risk Pools: These were created specifically for patients with high-cost, chronic conditions. The pools were very expensive and often unavailable because of overenrollment.

We sometimes view healthcare as slow moving, but the ACA reforms that positively affected the list above happened relatively quickly, and have had a positive impact on the bleeding disorder community.

Why should you know all these insurance terms and concepts? Because it's essential to have a basic understanding of basic insurance language if you want to become a healthcare champion!

Coinsurance: The percentage of costs of medical services paid by the patient. Coinsurance usually is about 20% of the cost of medical services after any deductible is paid.

Copayment: A cost-sharing arrangement in which a covered person pays a specified charge for a specific service, such as a fixed dollar amount for each prescription received. Example: \$5.00 per generic prescription, \$10.00 per preferred brand-name prescription, and a higher charge such as \$25.00 for a non-formulary product.

Deductible: A fixed amount of healthcare dollars the insured is required to pay under a health insurance contract, before benefits become payable.

Out-of-Pocket Limit: The most you have to pay for covered insurance services in a plan year. After you spend this amount, your private health plan pays 100% of the cost of covered benefits.

continued on page 11

Ask the Expert

Michelle Rice
Senior Vice President, External Affairs, National Hemophilia Foundation

Q: Recently I received a notice from my pharmacy benefit manager (PBM) stating that the amount paid by my factor manufacturer assistance program does not count toward my deductible and copay. Is this correct?



A Unfortunately, yes. Health plans, specifically high-deductible plans offered by self-insured employer groups, have implemented one of two programs designed to drive savings by ensuring that patients personally share in the cost of healthcare. The programs are often called either an “Accumulator Adjustment Program” or a “Copay Maximum Allowance Program.”



Q Why were these programs implemented?

A The PBMs argue that a patient who has no “skin in the game” will potentially choose higher-cost drugs and get unnecessary tests, procedures, and labs. PBMs also worry that a manufacturer’s copay assistance programs can be used to incentivize patients to choose non-preferred drugs (such as the manufacturer’s) without considering cost, because the patients’ out-of-pocket cost would be zero.

Q But this means that our costs are higher, or that we may not be able to get the drug we want or need. What is NHF’s position on these programs, and what is it doing to help patients?

A NHF sees the value of using cost reduction programs or other mechanisms aimed at lowering payer costs only when generic alternatives are available or the medications are considered low value (not necessary). NHF strongly feels that adopting these programs for patients who use high-cost or high-value (lifesaving) drugs with no generic alternatives, and who have high-deductible plans, have the reverse effect—leading to increased costs for both patients and payers.

NHF is partnering with National Alliance of Healthcare Purchaser Coalitions, a national nonprofit 501(c)(6) that is a membership organization of purchaser-led healthcare coalitions (self-insured employer groups or institutions), to produce and deliver a webinar to its member agencies including self-insured employer groups. The webinar will explain the unintended consequences that cost reduction programs may have on people affected by chronic conditions requiring high-cost, specialty therapies with no generic alternatives.



Get Out of Jail Free—This Time

Ian Thomas

It's hard to imagine that \$86 almost cost us our health insurance and resulted in financial hardship. But our story shows how careful you must be when dealing with health insurance. One slipup can almost ruin you, financially and medically. We want to ensure that no other family with bleeding disorders has to go through what we did. Thankfully, our story had a happy ending.

In mid-February 2016, I was notified by University of Kentucky HealthCare Hemophilia Treatment Center (UKHTC) about a billing issue with two shipments of factor from January and February of 2016. UKHTC (our factor provider and medical provider) informed us that reimbursement for the two shipments of factor was being rejected by Anthem, our insurance company, due to termination of my policy. *Termination?* I had already paid my premiums for January, and I was getting ready to pay February's premium. What had happened?

I reviewed my notes and my memory to get the most accurate account. In late December 2015, I had called Anthem to add my wife Elaine to my insurance

policy. I'd spoken with a representative, whose name I documented (though I didn't document the call's recording number). She added Elaine, which increased my monthly premium for December. I paid the December balance over the phone, and I recall asking the rep at least twice what my new monthly balance would be. She told me \$530 and some change. So I went ahead and also paid the January 2016 premium over the phone, \$530, and thought it was taken care of.

In the first week of January, I received a bill for an odd amount, \$86. I had no clue what this was for. Under the amount was a statement like "Please disregard if you have already sent your payment." No big deal, I thought to myself. I had just paid the January premium of \$530. I even checked my bank account to ensure that the payment had gone through. I assumed the \$86 invoice must have been an error. I didn't give it another thought. Big mistake!

In the first week of February, I received my monthly insurance bill, which showed the amount due was higher than \$530. At that time we were struggling financially, and I waited until the middle or later part of the month to pay my premium, knowing that I had a 31-day grace period. When

I called Anthem to set up an over-the-phone payment, I was informed that my policy had been canceled because I hadn't paid the premium in full in January. I felt confused, then frustrated. What had happened, and how could I fix it?

I told the Anthem rep about my January payment of



Thomas family: Elaine, Ian, and baby True

\$530. She said that wasn't the correct amount. Apparently, our monthly premium had increased to \$616 in January 2016! So I owed \$86 for January, and because it hadn't been paid by the end of the grace period (beginning of February), my policy had been terminated.

I told the rep about my previous phone call with Anthem, adding my wife to the policy, and the monthly quote I was given. She determined that the quote was correct—for 2015! It did not take into account the premium increase for 2016. *Really?* She asked why I had not responded to the January bill. I told her the bill had said to disregard if I had already paid. I asked to hear the recording of the initial call. But I hadn't documented the recording number, and she couldn't track it down. We'll never know if I misunderstood the initial quote, or if I received wrong information.

In the meantime, I applied for reinstatement to Anthem, but this was denied. I called our HTC social worker, Julia Kluesner. Julia helped me appeal the case before Anthem, but the appeal was denied.



continued on page 13

Community Forum

We've asked three community members to weigh in on the Affordable Care Act and its possible revision or repeal.

Bob Graham gives us a community advocate's perspective. Joy Fitzgerald offers her family's experiences with the ACA.

James Romano responds from a payer's point of view.

Q: What concerns you most about revising or repealing the ACA? What provision(s) do you think need revising?



Bob Graham

Public Policy Coordinator,
New York State Bleeding
Disorders Coalition
Director, BDAN Family
Camp, New York

I'm concerned the bleeding disorder community isn't making the best case for why the healthcare reforms we want are good public policy.

The ACA passed Congress with no Republican votes, due partly to partisan politics, and partly to differences on underlying issues of healthcare and the role of government. The recent vote by the House of Representatives shows these differences remain a strong, dividing force. Before we focus too much on the details of proposed revisions, we need to refine our approach to the entire healthcare debate. Here's how:

First, establish a larger, connecting narrative. Americans often have complex views on issues; witness the many who benefit from the ACA yet support candidates pledging to repeal it. People will often rely on what they think of the values, ideas, and interests driving a debate, especially if they lack the time and expertise to sort out the details of an issue.

One example of a larger narrative is "I believe a country of healthy, financially stable people who can work, go to school, and care for their families will be prosperous and secure." While simplistic, this narrative helps explain why you might

want to ban high copays, and also allow patients to receive help paying their coverage premiums. Having a larger narrative gives you a greater chance of finding common ground with others and continuing the discussion toward a possible agreement.

Discussions over healthcare will be taking place for a long time. They'll occur within the context of a larger narrative. Make sure a narrative supporting your position is part of the discussion.

Second, facts matter. Our community has a growing body of research-based evidence and data to support the use of prophylaxis, to explain why some products work better for some patients, and so on. Having facts at hand is crucial to making a logical case for the reforms we want.

Legislators, policy officials, and health plan administrators also must answer to those who disagree with us. Providing logical arguments, backed by verifiable information, helps those in a position to make important decisions support our proposals. This is crucial because our proposals often come with a significant cost to the government, taxpayers, and patients.

Personal stories may put a face on logical arguments. But they aren't enough to sustain major policy changes, especially when the cameras are off and the opposition offers its well-prepared, factual counterarguments.

Third, be very intentional in your choice of words. Certain words used to make a case for a policy are as important as the terms used in the policy itself. The right words can convey entire concepts and ideas within a larger argument.

For example, *choice* is often seen as a convenience, something people can pay extra to get. *Access* is seen as the ability to get an essential need met. Nice vs. neces-

sary; optional vs. essential. The same is true for the term *bleeding disorder*. Unless you are discussing product X, which is used to treat disorder Y, use "bleeding disorder" when describing the community. This covers a much larger group of people than any specific disease term, and being part of a larger community makes us more relevant to legislators.

Words have the power to make a narrative resonate with a wider audience and drive home an argument. Leading political figures are careful to use—or not use—certain words for this reason. The careful, consistent use of the right key words is critical; it can help make or break our entire position.

Many Americans are not yet convinced that the healthcare reforms started by the ACA are good public policy. The bleeding disorder community must do everything it can to make the case for healthcare reform in general if we want many of our specific proposals to pass.

Q: Did the ACA have a positive or negative impact on your access to care? What additional changes would you like to see?



Joy Fitzgerald

Marketing/Education
Manager, GCS, Inc.,
Maryland

My husband is self-employed. We had small-group health insurance. All the ACA did for us was allow our children to stay on until age 26. The other benefits of

the ACA we already had on our plan. Our son, age 11, has hemophilia A. Our daughter, age 28, has von Willebrand disease (VWD), though she is no longer on our health insurance.

This is how the ACA hurt us:

Our premiums for our family went from \$1,000 per month to \$3,000 per month. I went from paying \$20 for doctor visits with no deductibles, to having copays and deductibles for everything: office visits, hospital, X-ray, labs, and more.

I now have copays and deductibles for all our prescription drugs, with factor (\$6,000 deductible; \$150 per month copay) being the highest priced.

I also lost the freedom to choose my specialty pharmacy. A year ago, my insurance allowed me to go out-of-network to keep my specialty pharmacy. This year, with my new insurance, I have few choices—only one in-network and no out-of-network. The insurance company said, “You use this one pharmacy, that’s it.”

Our plan requires that I use one of the big-box store pharmacies, which I tried (three years ago, and then switched to an out-of-network option). I don’t like that they are unable to help in an emergency or when we’re on vacation or have travel issues. But most of all, these pharmacies put my child’s life in danger because they send the wrong supplies, and they can’t get supplies in time. They couldn’t work with our hemophilia treatment center (HTC) or hospital to get factor delivered for five days after our son had been discharged from surgery (after confirming to me, the hospital, and my HTC nurse that I would have delivery by 10:00 am)—because the pharmacy doesn’t have supplies in stock. Then they miss the cut-off time for shipment, and then they miss the plane because...I don’t know why! It

took five days to receive the supplies, and we had to return to the hospital.

That’s why I dislike the ACA: freedom of choice is so important, not only in doctors, but in pharmacy.

I have friends who are on disability. Once they’re on Medicare, manufacturer assistance programs cannot be used to help with their copays and deductibles. So patients have to find a means to pay, or go without.

Right now my family is fighting again, because of January insurance changes, to get my son’s factor (we want to switch to a different product, which isn’t covered) and to use our pharmacy of choice. It took from January to May to get approval by appeal, and we didn’t have factor delivered from February to May. The new factor was approved by insurance on May 2, and the insurance company’s approved specialty pharmacy sent the wrong supplies. It’s really hard to use my son’s port with the wrong needles! I sent them a picture of the correct needles, and they still can’t get it right. Although ports mean a sterile procedure, they sent me boxed gloves instead of individual sterile gloves—and with latex, for a person with a latex allergy. Just too many mistakes.

The state I live in has only one Marketplace option for health insurance, with many different plans to choose from. All the other companies have dropped out and no longer sell health insurance in my state. So that’s why we have changed insurance again, during open enrollment, and the fight continues. I was once a stay-at-home mom, but I returned to work to provide health insurance for my family that did not cost us \$3,000 per month. I’m lucky that I’m able to work from home, and my company understands my son’s medical condition so I can set my own hours. But it’s hard to find a job like this!

Q: What part of the ACA had the biggest impact on payers?



James Romano
Director of Government
Relations and Advocacy,
Patient Services, Inc.,
Virginia

The biggest impact on health insurance providers was the inclusion of the patient protection provisions, which patient advocates have long championed. Protections include the removal of the preexisting condition exclusion, annual and lifetime limits, and coverage rescissions.¹

This major policy change was a result of a compromise between health insurance providers and the Obama administration. The ACA mandated that all Americans obtain and maintain health coverage they could afford, with a tax penalty for not complying. In theory, the mandate would create a new market including potentially younger, healthier customers. The risk would be spread across the insurance pool to offset the inclusion of people with rare diseases and chronic illnesses.

The law also wanted to protect insurance providers from the high cost of the influx of patients with rare and chronic illnesses. These “offset programs” were Reinsurance, Risk Corridors, and Risk Adjustment.

The ACA Reinsurance Program provided payments to plans that enroll higher-cost patients whose medical claims exceed certain thresholds. This temporary program ended in 2016. The ACA Risk Corridor Program worked to limit plan losses, taking funds from plans with lower-than-expected claims and providing those funds to plans with higher-than-expected claims. This temporary

continued on page 15

1. According to Healthcare.gov, rescission is the retroactive cancellation of a health insurance policy. Insurance companies sometimes retroactively cancel an entire policy if the insured made a mistake on the initial application. Under the ACA, rescission is illegal except in cases of fraud or intentional misrepresentation.

Tracks & Trends



For Americans under age 65, drug prices are forecasted to rise 11.6% in 2017—slightly more than prices for Americans over 65. These increases cause patients to go without medication and some drugs to be dropped from drug formularies by health insurance providers.

www.cbsnews.com

US patients are

expected to spend over \$50 billion out-of-pocket on prescription drugs in 2017. Through Medicare, Medicaid, and other programs, the federal government is expected to pay \$126 billion.

www.aging.senate.gov



State governments are pushing for greater transparency from health insurance companies so patients have easier access to cost, quality, and copay data to make informed choices about their health insurance policies. Insurance commissions and state legislatures in California, Florida, Maryland, Oregon, and

New Jersey have enacted regulations and legislation to establish online sites that patients can use to compare prices and charges for common procedures.

healthaffairs.org



Healthcare now costs

twice as much as it did in 1996.

www2.deloitte.com



For an average employer-insured patient, the average out-of-pocket cost for treating an upper respiratory issue is \$41 at a retail health clinic. The average cost for the same treatment for the same patient at an ER is \$650.

www.bcbs.com

The insurance market for the Affordable Care Act has been destabilized by President Trump's executive order relaxing enforcement of the "individual mandate," which requires all individuals to show proof of qualifying health coverage or pay a fee. To maintain

low costs, insurance companies need a mix of healthy and sick people to spread risk. Without the mandate, insurers fear that young, low-income, and healthy people will opt out of buying insurance, leaving the more expensive sick and elderly.

www.wsj.com



40% of US patients will seek care from more than 3,000 retail health clinics in 2017, as opposed to visiting an ER. That number is set to rise significantly: 88% of patients asked said they would go to a retail health clinic in 2018.

www.pwc.com



Prior Authorization: An administrative tool used by health plans that requires prescribers to receive pre-approval for prescribing certain drugs to qualify those drugs for coverage under the terms of the pharmacy benefit plan.

Keeping Your Head above Water: Understanding Insurance Plans

When you shop for a car, you do your research. Same goes for buying a new phone. Why not do the same thing when selecting insurance?

Sometimes it's tough to find answers to your insurance questions. But it's not impossible if you understand the terminology. Let's start with the basics. There are three major types of insurance:

1. Private or Commercial Plan: Insurance plan that is not part of a government insurance program (such as Medicaid or Medicare). Often, premiums are shared with an employer. Examples: companies such as United Healthcare and Anthem.

Third-Party Payer: Public or private organization that pays for (or "underwrites") coverage for healthcare expenses for another entity, usually an employer, such as Blue Cross Blue Shield, Medicare, Medicaid, or commercial insurers.

Managed Care: System of providing healthcare (for example, by an HMO or a PPO¹) that is designed to control costs through managed programs in which the physician accepts payment ahead of time on the amount charged for medical care, and the patient is limited in the choice of a physician.

Self-Funded/Self-Insured Healthcare Coverage: Health services that are delivered by providers; but the member's employer, not the insurance plan, bears the risk for any expenses incurred.

2. Medicaid: Healthcare program that assists low-income families or individuals in paying for long-term medical and custodial care costs. Medicaid is a joint program, funded primarily by the federal government and run at the state level, where coverage may vary.

3. Medicare: Federal health insurance program for people 65 or older, certain younger people with disabilities, and people with end-stage renal disease. Medicare Fee-for-Service (FFS) consists of two main parts: A and B. There are two additional parts to Medicare: C and D.

Part A (Hospital Insurance): Covers most medically necessary hospital, skilled nursing facility, home health, and hospice care.

Part B: Provides benefits to cover the costs of physicians' professional services, whether those services are provided in a hospital, a physician's office, an extended care facility, a nursing home, or an insured's home.

Part C (Medicare Advantage): Plan administered by a group of private health insurance companies approved by Medicare health insurers. Similar to a managed care plan.

Part D (Medicare Prescription Drug Benefit and Medicare Advantage Prescription Drug Plan): Provides benefits to cover the costs of outpatient prescription drugs. Administered through private health plans.

Go Ahead, Dip Your Toe in the Water!

It's important to take time to understand the basics of insurance, whether public or private. Often, you'll have a summary of insurance coverage that will give you a high-level understanding of what your plan does and does not cover. Take the time to read through it. Talk with your friends or family about their understanding of insurance—you never know where an expert is hiding! Friends and family may also give you pointers on what has been helpful for them.

And don't underestimate the value of the social worker at your HTC or clinician's office; these professionals deal with insurance issues constantly, and they may have great suggestions for you. Same goes for the reimbursement specialists at your specialty pharmacy or HTC. They spend a lot of time dealing with insurance companies, submitting insurance claim forms, and coordinating denials. They may have more expertise than you think.

Setting the High-Water Mark

Are you becoming a healthcare champion? Ask yourself these questions:

- What are you currently doing to make sure you have the best health insurance coverage for you and your family?
- Are you confident that you're up to speed on your current insurance coverage benefits?
- How closely do you currently follow healthcare issues in the news?

1. HMO (Health Maintenance Organization): Type of health plan that usually limits coverage to only doctors who work under contract with the HMO. Enrollees normally pay a monthly set fee that is not directly tied to actual health insurance costs. PPO (Preferred Provider Organization): Type of health plan that contracts with medical providers, such as hospitals and doctors, to create a network of participating providers. Enrollees pay less for care if they use the providers that belong to the plan's network.

- Do you know if you have commercial- or government-sponsored health insurance?
- Do you leave healthcare decisions to someone else? Have you asked yourself why?
- How has your insurance situation changed over the past several years?
- Do you ever discuss your insurance with your HTC or other healthcare professionals?

5W1H: Build Your Personalized Plan

Having a personalized healthcare plan and knowing where to go for help and information will provide a measure of certainty in the coming years. When I face uncertainty, I always use the acronym 5W1H: who, what, where, when, why, and how?

Let's see how we can use 5W1H to begin creating a list of questions related to health insurance.

- Who at my employer or insurance company should I talk to if I have a problem?
- What information do I need to gather?
- When do I need to update or reenroll in my insurance?
- Where can I go to get the necessary healthcare information?
- Why is it so important to keep a list of the people I talk with at my insurance company?
- How much will my insurance cost me per year? How can I budget for this?

When you visit your healthcare professional, write a list of questions ahead of time. I usually jot down questions on a post-it note and stick it on my insurance card. This way, I'm certain that I won't forget! Find out what type of communication works best for you and your clinician: maybe emails are the best route; maybe an online portal; maybe the doctor wants to talk with you right away. Don't be afraid to bring someone with you to an appointment. Sometimes it's easier to have a friend or relative ask the tough questions or make sure you fully understand what's being discussed.

If you're unsure about the guidance your clinician has given you, don't leave the office until you're comfortable. Then, as soon as you leave, write down the key facts that were discussed. Even better, sit down with someone that night and talk about what was shared with you. There may be times where you think you heard one thing, but a few hours later you're not sure; this kind of information needs to be clarified. National Hemophilia Foundation (NHF) has a great toolkit² to help you create questions and develop

your personalized healthcare plan—a plan that's focused on your healthcare needs and tailored specifically to you. Just as no two people are alike, the same goes for your healthcare plan. Think personalized!

Jump In, Start Swimming

Remember, your personalized healthcare plan doesn't have to be extremely detailed or contain a bunch of fancy terms, but it does need to be specific for you and able to be adjusted if necessary. Make the commitment to making your plan personal.

Think of what Craig did. He created a plan, implemented it, and then adjusted it as his healthcare situation changed. In the end, he was freed from a financial burden and gained more certainty in his life.

Over the next week or two, make a promise to yourself to become a healthcare champion, and begin creating your own personalized plan. Often, the hardest part is dedicating the time to get started. It may be a good idea to share your plan with someone else and work together to set specific goals for yourself. This doesn't mean that you have to create a formal plan. What it does mean is that you're beginning to take control of your own healthcare journey, and that you're taking a lot of the uncertainty out of your life.

When creating your plan, think 5W1H: who, what, where, when, why, and how? You'll be surprised how easily you can progress when you start with these simple words. Read the resources available to you, and don't be afraid to seek help from others. They'll probably be happy that you did ask, because there's a good chance you may help them at the same time. That's what being a healthcare champion is all about.

What's Next?

We may not have a crystal ball to tell us the future of healthcare, but we do know that coordination between healthcare providers and health plans will increase, and that patients will have a lot more say about their own healthcare. These changes will also bring the consolidation of hospitals, health plans, and physician practices. Health insurance companies will demand that they get the best value for their money, and that their patients' health improves. We also know that patient out-of-pocket expenses will probably increase as the government and employers try to manage the skyrocketing costs of services, procedures, and drugs.

Change is never easy. The uncertainty it brings can cause many of us to fear the future, but this doesn't have to be the case.

2. www.hemophilia.org/Advocacy-Healthcare-Coverage/Advocacy-Tools-Resources/Personal-Health-Insurance-Toolkit

Creating a personalized healthcare plan of action and dedicating yourself to being your own healthcare champion can ease the fear of the unknown, and can help you set a path for certainty in the years to come. —

Michael Bradley is vice president of business development for the Access Group. Before consulting, he spent 24 years at Baxter, Baxalta, and then Shire. He has been involved in the bleeding disorder community for over 30 years and is currently vice president of Hemophilia Council of California.

Additional Financial Assistance

Did you know that most factor manufacturers have financial assistance programs to help you pay your insurance copays, coinsurance, and deductibles? Both Hemophilia Federation of America and National Hemophilia Foundation have great overviews of these programs on their websites.

NHF: www.hemophilia.org/Newsroom/Advocacy-Legislative-News/Find-Patient-Assistance-Programs-to-Help-Cover-Your-Insurance-Costs

HFA: www.hemophiliafed.org/resource-library/additional-resources/navigating-patient-assistance-programs/

HFA Dateline Federation: www.hemophiliafed.org/uploads/HFA_Dateline_Special-IssueG.pdf

Shire: 888-229-8379

Bayer HealthCare: 800-288-8374

Bioverativ: 855-692-5776 (Alprolix)

855-693-5628 (Eloctate)

CSL Behring: 800-676-4266

Aptevo Therapeutics: 855-494-6489

Grifols: 844-693-2286

Novo Nordisk Inc.: 844-668-6732

Octapharma USA: 800-554-4440

Pfizer Inc.: 888-240-9040

My Life from page 7

By then, I had already received my January and February factor shipments from the UKHTC pharmacy—before I ever knew about the insurance problem! The HTC worried that if my insurance weren't reinstated, I would eventually be billed for the factor, to the tune of \$63,000. This had become a serious issue with an uncertain outcome.

Now the questions began: Who's responsible for paying the outstanding bill of \$63,000 for the factor shipped? Me? The UKHTC pharmacy always confirms coverage with Anthem before any shipment can occur. How could I have received the factor if I wasn't covered? How do I get my insurance coverage back, with enrollment only once a year? How do I order factor for March?

This was potentially devastating financially for my family. I couldn't pay the \$63,000 or pay to fight a legal battle. I'm a self-employed, first-generation farmer. In the last two years, the US farm economy has tanked from low commodity prices. Our farm operation has seen a lot of red ink. It has been a struggle to keep our heads above water.

I went through March with no healthcare coverage, surviving only on donated factor through our factor manufacturer's compassionate care program.

Then Elaine was promoted to full time at her work, enabling us both to have coverage in April. This was an absolute blessing!

I reached out to the hemophilia community for advice. My mother contacted Laurie Kelley, who was on the case immediately. Laurie put me in touch with an insurance expert at National Hemophilia Foundation. I continued speaking with Julia, who was extremely helpful as well. And I talked with our attorney and my uncle, Bob Massie.

We basically had to fight Anthem to get the factor covered, or work with UKHTC in negotiating the bill. Elaine and I weighed the possible outcomes. I felt I had a legitimate case with Anthem. But I worried that I had made a mistake or misunderstood something, and would still be responsible for the bill, plus legal fees. On the other hand, I certainly didn't want to saddle the HTC with our bill.

Eventually, the UKHTC pharmacy billed me \$63,000 for the factor, but we negotiated the bill to \$0. How? We had a loss from farming on our tax return, which allowed us to have the bill erased. We're thankful that the issue was settled, but I didn't like having the UKHTC pharmacy pay the bill. I wish we'd gotten Anthem to reimburse the HTC, and I

think there was a legitimate case for Anthem to pay our claim.

Now, I watch like a hawk anything and everything insurance or medical related. We were given our "get out of jail free" card, and I don't want to be in that situation again. My message to everyone else in our community: 1. Document every call you have with insurance companies, and get every number or code. 2. Check all bills and read all letters and policies, monthly. 3. Engage your HTC to help you with insurance claims. In this age of healthcare uncertainty, it's more important than ever to safeguard your policy, services, and factor supply by reading, asking, and challenging the system. —

Ian Thomas has severe hemophilia A, and lives in Kentucky with his wife Elaine and their new baby boy, True. Ian is a first-generation farmer, raising cattle and crops on 750 acres. Ian and Elaine work for a crop insurance agency in Kentucky, and are passionate about agriculture and rural life. They're active in the Episcopal Church and local community, serving on boards of several organizations. Ian's grandparents are Robert K. and Susanne Massie, authors of Journey, a book about the life of Ian's well-known uncle, Bob Massie, who was cured of hemophilia following a liver transplant.

Michelle Alabek, genetic counselor at the Institute for Transfusion Medicine, advises parents and relatives of potential carriers, "Talk to your daughter or female relative about genetic testing for carrier status, share information with her, and help her understand why this could be so important." For example, knowing carrier status before a medical procedure can help prevent bleeding complications. Equally important is testing factor levels of girls with a family history of hemophilia at as early an age as possible. "If we know someone is a carrier and at risk for bleeding with a procedure, I can develop a proactive plan with a carrier to minimize bleeding risk," says Alabek. "Without this management plan, a female may have avoidable bleeding with or after the procedure, which can lead to negative health outcomes."

According to MASAC, 50% of women and girls who are carriers for hemophilia also have factor levels below 50%, putting them at risk for excessive bleeding during delivery of a baby as well as during a surgery, accident, or menstruation.⁶ Carriers who plan to become pregnant need to know their factor level and create a bleed management plan for delivery. Having a plan is critical in avoiding complications for both mother and baby.

According to Bradbury, "If the genetic variant that causes bleeding is known, then you can make choices about options for genetic testing pre-conception and post-conception. An informed mom-to-be

can work with her ob/gyn to create a delivery plan using MASAC guidelines. A plan may include having factor on hand, avoiding the use of assistive delivery devices, and planning for procedures, like circumcision, after a baby is born."

It's also important that your daughter understands the risks of being tested. These range from emotional impact to potential genetic discrimination. When a woman learns she's a carrier, she may feel anxious, depressed, angry, or guilty. "Genetic testing can elicit a variety of emotions," explains Alabek. "Individuals within the same family may respond differently to the same results, so having genetic counseling ahead of time can help a woman with the psychosocial aspects of testing, promote informed decision making, and anticipate reactions to the different possible test results."

What about the risk of genetic discrimination? After 13 years of trying, in 2009 Congress barred health insurance companies from denying coverage to people with a genetic mutation and prohibited genetic discrimination in employment by passing the Genetic Information Nondiscrimination Act (GINA).⁷ But this hard-fought win doesn't mean that your daughter is free from genetic discrimination. GINA does not apply to employers with fewer than 15 employees who provide health insurance to their employees. GINA also does not apply to other types of insurance, such as life, disability, or long-term care insurance.⁸

Even so, Ghate stresses, "The medical benefit of genetic testing when offered by professionals with expertise far outweighs any risk of group health insurance discrimination." She notes, "Genetic counselors can answer your questions about genetic testing and insurance discrimination. As a genetic counselor, I often address questions related to health insurance discrimination and am familiar with both federal laws and state laws, which helps me allay fears about insurance discrimination."

The Price of Privacy

For privacy reasons, some people choose to pay out-of-pocket for genetic testing so that the testing and results do not appear in their medical record. Those costs range from \$200 to \$3,000 plus.⁹ Ghate recommends asking a genetic counselor about the actual cost of testing. "If the specific causative mutation has been identified in the affected family member, carrier testing cost is quite reasonable, with the cost varying by lab and specific mutation." She explains, "In 2017, eligible potential carriers can seek carrier testing at no cost through the My Life Our Future program at qualified hemophilia treatment centers." If you do not receive care at a hemophilia treatment center (HTC), Bradbury recommends that you visit the National Society for Genetic Counselors website (www.nsgc.org) to find a genetic counselor. For more on My Life Our Future and a list of HTCs participating in the genetic testing program, visit www.mylifeourfuture.org.

Experts agree that it can be empowering to know if you're a carrier of a genetic mutation that causes hemophilia. "A woman who knows her risk of passing a bleeding disorder on to her child can better advocate for herself," Bradbury believes. It's your turn to talk to your daughter about genetic testing to determine if she's a carrier. Empower the girl, empower the woman. It could save a life. —



6. "MASAC Recommendations Regarding Girls and Women with Inherited Bleeding Disorders," <https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC/MASACRecommendations/MASAC-Recommendations-Regarding-Girls-and-Women-with-Inherited-Bleeding-Disorders> (Nov. 16, 2016, accessed May 3, 2017). 7. Farr, "If You Want Life Insurance, Think Twice Before Getting a Genetic Test." 8. "What Is Genetic Discrimination?" Genetics Home Reference, US National Library of Medicine, National Institutes of Health, <https://ghr.nlm.nih.gov/primer/testing/discrimination> (accessed May 3, 2017). 9. "Frequently Asked Questions About Genetic Testing."

program ended in 2016. The ACA Risk Adjustment Program redistributes funds from plans with lower-risk enrollees to plans with higher-risk enrollees. This is a permanent assistance program.

But insurance providers looked for additional policies and procedures to limit their perceived costs. Even with these programs in place, insurance providers found ways to maximize healthy enrollees and minimize rare-disease patients. Their policymaking partners in the Department of Health and Human Services developed a rule allowing plans to prevent the acceptance of third-party premium assistance from all but government programs. Although the ACA instituted patient protections that the patient advocacy community had long advocated, plans have spent nearly a decade attempting to chip away at those protections.

Many of the preceding offset provisions were a temporary way to protect insurance providers when the Marketplaces began. The combination of a risk pool with older, sicker individuals, along with the ending of temporary offset programs, has led insurance providers to pull out of state and federal Marketplaces. Policymakers and legislators are looking to address this ongoing problem.

Q: What do you think is the most pressing provision that needs to be revised?

Many patients with rare diseases and chronic illnesses rely on the ACA for access to health coverage through private commercial coverage in the individual and group markets, as well as public coverage through Medicare and Medicaid. The continuation of this coverage is critical for rare disease patient populations. However, within the last 18 months, insurance providers in some states have been withdrawing from the Marketplaces. There is a significant risk that certain rural geographic areas could go without access to even one Marketplace plan. There are provisions that, if enacted, would strengthen the individual market, guaranteeing that patients could continue accessing these plans.

The most pressing revision would be strengthening the individual market in the Marketplaces. The establishment of a permanent reinsurance program at the Department of Health and Human Services would assist in stabilizing health insurance plans in the Marketplaces. Reinsurance programs spread risk for insurance companies to offset losses due

to higher than expected healthcare claims data. This would accommodate people with high-cost conditions and allow providers to accept patients with preexisting conditions. The Medicare Part D program contains a permanent reinsurance program to insulate from losses, contributing to its success and patient satisfaction.

Congress unfortunately let the reinsurance program lapse in 2016. However, states have moved forward to enact their own reinsurance programs, Minnesota and Alaska leading the way. The Alaska reinsurance program has reduced premium increases in 2017 from 42% to 7%, just by reimbursing insurers for exceptional claims. Ten states have petitioned the Centers of Medicare and Medicaid Services (CMS) and passed state legislation to begin these programs.

Reinsurance programs have the potential to limit risk for insurance providers while covering patients. Although many changes would improve the ACA experience, a reinsurance program instituted nationally would benefit insurance providers and rare disease patients. —

Let's Take a Quiz! Answers

1. Obamacare
2. a. No lifetime caps. b. Medicaid expansion in many states. c. Insurance cannot be denied if you have a pre-existing condition. d. Adults up to age 26 can receive benefits through their parent's private insurance policy.
3. Organizations set up to facilitate the purchase of health insurance in each state in accordance with the ACA.
4. Hemophilia = 25%–30%; WVD = 20%–22%
5. Most factor manufacturers have financial insurance assistance programs to help consumers with private insurance (see page X for phone numbers). Other
- fact that there are major differences between to two parties.
6. No and No. The primary goal of the ACA, which was backed by the Democrats, was to make sure that most Americans obtained health insurance. Republicans, on the other hand, want to make health insurance more accessible and more affordable so that people can buy policies. Though we can argue that neither of these will truly happen, this contrast does point to the fact that there are major differences between to two parties.

Stability through premium assistance and disability representation.

PSI
Patient Services, Inc.

www.patientservicesinc.org
1.800.366.7741



37-39 West Main Street, #8
Georgetown, MA 01833 USA

INSIDE:
Dealing with
Uncertainty
in Healthcare

September 2017

PEN's Insurance Pulse 
Inspiring Advocacy

You can improve the life of a
child with a bleeding disorder.

Our sponsorship program provides direct
assistance to children in developing
countries, who suffer the double burden
of a bleeding disorder and poverty.

To sponsor a child:
contact@saveonelife.net
or 978-352-7652

Sponsorships are
\$264 per year
(just \$22 a month!)



saveonelife.net

Sponsor a Child!

