

PEN's Insurance Pulse

Inspiring Advocacy

Inside

- 2** Welcome
- 3** **Transitions:** Preparing New Leaders
- 8** **Tracks & Trends**
- 10** **Ask the Expert:** Where Can I Get Help with My Insurance Policy?
- 11** **Real Life:** Fighting for Insurance
- 12** **Community Forum:** Resources for Navigating Insurance Reform



Mastering Your Fears: What's in Your Insurance Policy?

Laureen A. Kelley with Wendy Owens

Health insurance is a relatively new phenomenon. Early in the 20th century, people paid for “burial insurance” to cover funeral costs. Without many of the treatments commonly available today, people often died of infections. Consequently, insurers insured death, not health. In the 1920s, when the cost of dying became lower than the cost of missing work, people started paying for “sick insurance” (later, disability insurance) to cover lost wages. Then in the 1930s, as a result of medical advances and insurers’ ability to figure all the costs related to health, people—and later the government and employers—began paying for health insurance.

Over the past 80 years, the number of people paying for health insurance and the companies offering it have both increased. Today, for those of us lucky enough to have health insurance, the cost of this insurance continues to rise. Knowing what these rising costs cover is crucial to your health, your family’s health, and your financial

continued on page 4



Welcome

PEN'S INSURANCE PULSE

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Since I wrote my first book in 1990, insurance had always been my least favorite part of researching and writing. I dreaded it, much as I dreaded doing income taxes, following recipes, or solving sudokus. Too much work. But no book on bleeding disorders could be complete without a chapter on insurance. In fact, my latest edition of *Raising a Child with Hemophilia* had to extend insurance to two chapters! Now I find that I can not only write about insurance, but get

excited about it. And I'm also more confident about helping my own adult son solve his insurance challenges.

If you feel unsure about insurance policies, unclear about the Affordable Care Act (like many of our readers—just look at our poll results), and overwhelmed in general, this issue of *Pulse* is for you. Nothing would please me more than to build your confidence in handling your own insurance, and motivate you to learn more about your policy. You'll need to learn: insurance is a rapidly changing field, now more than ever. To protect our hard-earned achievements—choice of factor products and comprehensive care—we must know insurance terms, understand our options, and look toward the future of healthcare.

Insurance isn't something to fear; it's something to master. Income tax? That's a different matter!

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.

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insurance questions should contact their employer's human resource department, Medicaid or Medicare caseworker, payer representative, or HTC social worker.

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Passing the Baton: Preparing New Leaders

Richard J. Atwood

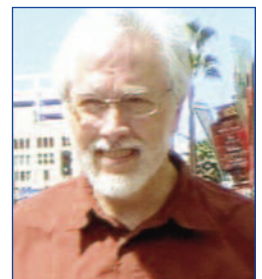
baton

Passing the baton. What exactly does that phrase mean?

The metaphor originates in track-and-field relay races: each runner on a team passes the baton, or a painted stick, to the next runner. Athletes run only part of the race while the baton travels the entire distance. A winning race requires good coaching, practice, and learning from personal experience.

In our bleeding disorder community, passing the baton also means the symbolic passing of leadership to the next generation. Our current leaders have accomplished a lot. We can thank them for running chapters, protecting blood safety, ensuring funding for treatment centers, and advocating for our needs. Think of just some of the important legislation that has been enacted on state and federal levels: the Ricky Ray Act, no lifetime insurance caps, and state hemophilia programs.

Yet our current community leaders are getting on in years. Who from the next generation will grab the baton? And will they be prepared?



Athletes Ready to Run

Pat first became involved in the hemophilia community by working at camp every year. He then became a member of National Hemophilia Foundation's (NHF) National Youth Leadership Institute (NYLI) before serving on the board of his state foundation in Michigan. As for Pat's hemophilia care, his parents

acted to ensure his medical coverage when he was younger, but now Pat knows to monitor his insurance himself.

Another young leader, Phil, began in high school by attending NHF Washington Days: he got to walk the halls of Congress and talk to his elected representatives. This was a life-changing experience for Phil, now a medical student, who explains, "It



Phil

continued on page 14

Mastering Your Fears *from cover*

**Courage is resistance to fear,
mastery of fear, not absence of fear.**

—MARK TWAIN

well-being. But even though we pay our health insurance premiums each month, many of us still don't know what our health insurance policies cover. Well, at least we can be pretty sure it isn't burials or lost wages.

Not knowing what's in your policy can make you confused and anxious, especially during a medical situation. "Most people do not engage and learn what their policy covers until a crisis happens," notes Alan Hurley, a benefits consultant and board member of New England Hemophilia Association. "People react to healthcare emergencies and are not prepared when they need to know whether their insurance covers the care they or their loved ones require."

What's in *your* health insurance policy? What type of plan do you have? Do you know how much your plan will actually cost you in a year? Can you choose your specialists? What happens to your plan if you lose your job?

If you're afraid of what you'll learn if you read your policy, you're not alone. Many people fear the process of selecting and then understanding a health insurance plan. In a recent survey of more than 1,000 adults, insurance giant Aetna found that 32% were confused about the cost of their insurance plan; 30% had trouble distinguishing between the different types of plans; 26% were confused about which providers were considered in-network; and 24% didn't know if their plan required referrals to specialists.¹ In-network? Referral? Yes, learning the health insurance lingo and what it means in your policy can be daunting. But you can do it.

Anxiety over health insurance coverage is normal. Policies are

becoming more complex and difficult to decipher. But that's no excuse to go blindly forward, fingers crossed, hoping that your policy will cover the healthcare you need. With a little time and the right focus, you can learn the benefits your policy provides—and even find out why you should treat your health insurance policy like a financial asset.

Selecting the Right Plan

Do you know if you need an HMO or a PPO, or even a POS or an EPO? Have your eyes glazed over yet? Selecting the right healthcare plan is where the anxiety starts. Open enrollment, usually a 30-day period, is the time of year when you have the opportunity to change health plans, even if you have Medicare. If you don't know when this period is for you, find out. Then start by doing some homework, so that when the time comes, you'll be ready to decide which plan is best for you and your family.

Figuring out which plan is right for you can be like deciphering US tax code. Not to worry. Tools and information from your employer and the insurance providers offering the plans, available during your open-enrollment period, will help you decide. Increasingly, insurance companies are posting these tools online. Check with your employer to see if potential insurers have the tools you need to compare plan options.

Remember, it may not be obvious which plan is best for you until you look at the plan's entire package. "Large employers often offer plans that


cost less and cover more," explains Cat Stulik, a social worker at Puget Sound Blood Center in Seattle. "For people with hemophilia working at small businesses, it may be cheaper to purchase high-risk insurance than pay for the plan through their employer. People need to explore all avenues to make sure they get the coverage they need at the best price."

Get ready, because here comes the anxiety again. If you have a bleeding disorder, or your family member has one, you'll need to dig deeper into policy offerings to make sure a plan meets your specific needs. This will take effort. Before you start to fret, help is available. National Hemophilia Foundation's "Health Plan Comparison Guide" is available on the NHF website. The guide focuses on two key elements of any health plan: cost and benefits. It can help you think through your healthcare needs, for example, what services and medication you require. The guide also helps you calculate costs, such as total out-of-pocket costs for copayments, deductibles, and coinsurance. The guide also helps you review each available plan for things like coverage of clotting factor, whether your hemophilia treatment center (HTC) is in the plan's network, and whether prior authorization is required for treatments.²

The Factor Factor

Once you have narrowed the choice of plans, it's time to *know* whether your factor is covered by the particular plans that seem to best suit your needs. So

1. "Consumers want more choices but are confused by plan options," *Managed Health Executive*, March 2012. 2. Find NHF's guide under "Personal Health Insurance Toolkit" in the Advocacy section of the NHF website at www.hemophilia.org.



ask the *right* person for help in determining this. “Find the right insurance representative who can tell you without a doubt that clotting factor is covered by a plan,” advises Stulik. “Because there are so few people with hemophilia, the average customer service rep who takes your call often is not familiar with clotting factor. Once I had a patient call an insurance company during open enrollment. The patient asked if a plan covered clotting factor. The customer service rep said yes, the plan covered all ‘blood products.’ It ended up that the insurer did cover blood-derived products but not recombinant factor. The rep did not know about hemophilia or clotting factor so they gave out the wrong information.”

Know *how* your factor is covered. Each year you need to review your policy carefully to determine whether your factor is covered as a *medical benefit* (also known as *major medical*) or as a *pharmacy benefit*. More and more insurers are moving factor from the medical benefit part of your policy to the pharmacy part. This allows them to place factor on a drug formulary tier under which a higher copay, coinsurance payment, or higher deductible may apply. A shift of your factor from medical benefit to pharmacy benefit can dramatically increase your out-of-pocket costs. Insurers can make this change *without warning* when your policy is up for renewal during your open enrollment. You need to keep your eye on the ball and know not only if factor is covered, but also how it is covered.

Medicare and Medicaid Aid

If you are enrolled in Medicare, you have access to the SHIP (Senior Health Insurance Assistance Program) and SHINE (Serving Health Insurance

Needs of Elders) programs in your state. Contact these programs for help in selecting the right plan for you. According to the Medicare website, SHIP and SHINE provide “free, unbiased and up-to-date health insurance information, counseling and assistance to Medicare beneficiaries of all ages and their caregivers. Counselors help older persons (and younger disabled Medicare beneficiaries) understand their Medicare benefits and other health insurance options.”³

If you are enrolled in Medicaid, you have access to health insurance benefits advisors in your state. Each state has its own Medicaid agency that you can contact to learn what plans are available. More and more states are requiring that Medicaid recipients enroll in managed care plans, versus pay-for-services plans. This may narrow your choices, so contact your state’s Medicaid agency and work with a representative to find the right plan for you.⁴

Improve the Quality of Your Healthcare and Benefits

When selecting a health plan, consider the quality of care you will receive. According to the Agency for Healthcare Research and Quality (AHRQ), quality of healthcare is what most Americans value most, but few know their plan options well enough to make an informed decision about which medical professionals they see and where they go for the best care.⁵

Quality of healthcare varies, but it can be measured by comparing doctors as well as hospitals. How to do this? AHRQ suggests all patients look for quality reports that include consumer ratings and clinical performance measures. Surveys such as the Consumer

Assessment of Health Plans (CAHPS) look at healthcare from the consumer’s point of view. The CAHPS survey asks consumers for their feedback on specific plans: for example, do doctors in the plan communicate well? How long are wait times? Do members receive the health services they need?

It’s also important to look at clinical performance of a plan’s healthcare providers. The Health Plan Employer Data and Information Set (HEDIS) measures how well a healthcare organization prevents and treats illness. For example, HEDIS measures whether a plan offers such benefits as breast screening, prenatal care, and eye exams to prevent blindness in people with diabetes. Ask your employer, Medicare or Medicaid office, or your health plan provider if a CAHPS or HEDIS survey report is available for your plan and providers before making your selection.

Now that you’ve done your research, you know which plan offers what and for how much, and you’re certain that at least one plan covers factor and offers you top-notch healthcare, it’s decision time. Look ahead to what your health needs will be in the future, but also look back at the services you and your family needed in the past. Select the plan that fits your needs. The perfect plan may be available to you. If it is, then take it; compromise only if you have to. The decision is yours.

Get to Know Your Health Insurance Policy

So now that you have a health insurance policy, how do you get to know it? A little upfront work to learn your current policy will save you time and potentially money in the long run. “Education and communication are the keys,” believes Hurley.

3. For contact information for a SHIP or SHINE program in your state, visit www.medicare.gov/contacts. 4. For contact information for the Medicaid agency in your state, visit www.medicaid.gov. 5. See www.ahrq.gov and search “choosing healthcare.”

"Understanding your health insurance policy can be confusing and absolutely overwhelming. This is why people get frustrated and simply stop reading," he says. "This is not the time to give up, though. Demand to be educated. Contact your insurer and have them walk you through your policy to make sure that it meets your needs. Read the brochures that your company and provider distribute to learn more."

Read your plan summary for starters. It's the first step in taking charge of your healthcare coverage. Your plan summary will give you a general overview of what your policy contains. The Affordable Care Act established a standard Summary of Plan Benefits. This is a document that your insurer must provide to you automatically each year. The summary uses standard vocabulary with uniform definitions, so, for example, the phrase "out-of-pocket limit" means the same thing in all policies.

Next, read your policy and any supporting documents from your employer and insurer to continue building on the base of knowledge your plan summary provides. The time it will take you to review your policy is worth the investment. For help, contact your human resource (HR) office, health plan administrator, insurer, employee union, or NHF and Hemophilia Federation of America (HFA). The social workers at your HTC also are available to help. "If a patient needs help understanding their plan, they can give permission for the social worker at their HTC to work with their insurer to determine what their plan covers," notes Stulik.

Treat Health Insurance Like a Financial Asset

Health insurance prevents you from having to pay all medical expenses out

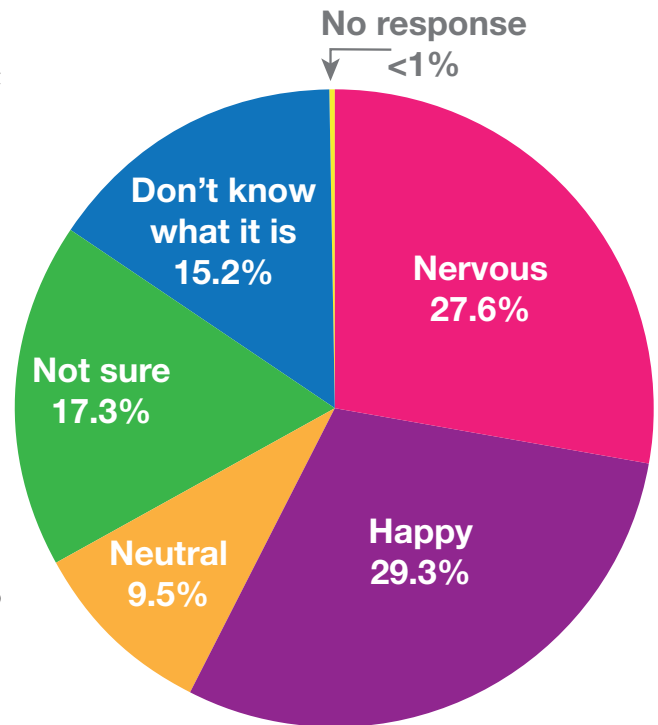
of your own pocket. Consequently, health insurance is an asset that works for you—but only if you choose your plan carefully and know what costs your plan will cover. If you don't know what your policy covers, you are turning over your healthcare and financial stability to someone else. Don't do it. Just as you check your bank statement monthly (or at least you should), check every bill for treatment you receive. Double-check the doctor or facility's name and the date of treatment. If you can't understand your bill, contact your healthcare provider. Request an itemized bill, and ask a staff member to review it with you. Contact your provider immediately if you find any problems with your bill, for example, if your insurance was not applied.

Often, billing mistakes are caused by improper application of a billing code—an easy fix, but only if you raise it with your provider. "I tell my patients the universal billing code, or 'J' code, for their factor," Stulik says. "Not only does this help them when they review their bill to know they were charged for the right medication, it's also helpful when they are considering changing plans. A customer service rep may not know what factor is, but they can look up the billing code for a factor product and tell a patient if a plan covers it."

Prevention and Coordination

Today, more insurance companies are focusing on preventive care and overall good health. You save them money

How do you feel about the Affordable Care Act?



Results of a study of 243 *Pulse* readers in April, 2012 (LA Kelley Communications, Inc.)

when you stay well because you eat right and exercise. It's likely that your policy includes wellness programs such as discounts on gym memberships, smoking cessation programs, and nutrition classes. Find out what your policy offers and make use of these programs.

If you are married, your spouse's employer may also offer a health benefits package. Find out what's in it, and then coordinate your two plans for maximum coverage at the best price. For example, your plan may allow you to see your regular doctor and preferred specialists without incurring any extra cost beyond a copayment. Your spouse's insurance may offer more affordable prescription medication benefits and allow you to use the home care company you choose. Coordinate your plans so

that you get the most healthcare for the least cost. Consider additional coverage for students, too. “College students may be able to stay on their parents’ plans, but they should consider the health insurance offered through their school. It may provide coverage for less or may fill in gaps in their parents’ insurance plans,” advises Stulik.

A Case for Knowledge and Asking for Help

Now you’re a little less nervous, and you think you have a handle on this policy thing. Good. Now you want proof that diligence pays off. Here’s a story for you:

Soon after Jackie Benson’s son David was born, 25 years ago, the family learned that he had hemophilia.⁶ Jackie’s health insurance policy had a \$1 million lifetime cap and covered David’s needs, including his factor. Once Jackie learned how expensive David’s prophylactic treatment would be, she decided to keep a close eye on the \$1 million cap and paid diligent attention to her policy, what it covered, and how much it covered. She kept records and carefully reviewed each statement of benefits. “I kept a three-ring binder with every explanation of benefits I received,” she recalls. For 25 years Jackie worked for the same company. During that time, she twice received letters from her insurer that David would soon reach his \$1 million cap. Jackie turned to her employer’s HR department for help. Twice the company switched insurers just in time, and each time David’s lifetime cap was reset with a new plan.

Last year, David was set to max out a \$2 million lifetime cap—only three months before the Affordable Care Act was set to take effect, allowing kids to stay on their parents’

How Confident Do You Feel about Insurance?

We surveyed 243 *Pulse* readers (76% have private insurance):

- **53%** feel **somewhat confident** about handling health insurance for themselves or a loved one with hemophilia.
- **66%** feel that insurance policies are **harder to understand** when they cover a chronic disorder like hemophilia.
- **70%** feel **very or somewhat confident** that they know the total cost of their insurance. **25%** are **not confident** (5% weren’t sure).
- **37%** go to their **insurance company** for support or questions about their policy. **36%** go to their **human resource director** or **HTC social worker**.

policy. Jackie again turned to HR. “I had filled out all the Medicare paperwork and was ready to turn it in,” she explains. “I figured I had nothing to lose by going to HR and asking if the company would cover David for three additional months. He would start his new job in that time, and then his insurance at his new job would kick in.” So HR took Jackie’s case to her employer’s board. The company decided to cover David for the three months. Jackie threw away the Medicare forms, pleased that she’d taken the time and the risk to ask. “People need to know their plans and just need to call and talk to their human resources people or whoever handles their plans,” she advises. “I feel blessed for the coverage David had. He participated in sports and did all the things he wanted to do as a child and teen. It would have been different for him if he had maxed out and not had access to prophylaxis.” Thanks to his mom’s vigilance, David did all the things he wanted to do as he grew up.

Get Started Now

Lifetime caps may no longer be a threat to people with chronic diseases (though the Supreme Court will soon cement this in place or bring it crumbling down). But people with bleeding disorders face other insurance challenges. So there’s no time like the present to start the process of getting to know your health insurance policy. It won’t happen overnight, and you’ll need to make a determined effort to educate yourself. But that’s better than worrying about the what-ifs that may arise with you and your family’s health: What if I need medical attention while on vacation out of the state or country? Does my policy cover this? What if it doesn’t? What if I have a baby? What if I need surgery? *What if?* Remember, you don’t need to cave in to your fears and feel overwhelmed—help is available! Take advantage of all the tools and resources, and take charge of your own healthcare. —A

6. Names have been changed for anonymity.

How does the **Affordable Care Act (ACA)**

June 2012

Weigh In?

The Care

By 2014, who will ACA help?

26% of the population ages 19 to 64 who experienced a gap in health insurance in 2011

69% of those with a gap who went without coverage for 1 year or more

45% of adults who tried but failed to buy a plan (mostly because of costs) in the past 3 years

Source: "Gaps in Health Insurance: Why So Many Americans Experience Breaks in Coverage and How the Affordable Care Act Will Help," Commonwealth Fund, April 19, 2012

Medicaid Set to Help

The expansion in eligibility for Medicaid, beginning in 2014, will help an additional 16 million families in need. This expansion will be a required element of every state Medicaid program.

Source: Kaiser Family Foundation

Land of Confusion

More than half of 1,000 insured adults surveyed were unclear about aspects of selecting a health insurance plan: 32% reported being confused about the total cost of an insurance plan; 30% had trouble understanding the difference between plan types.

Source: aetna.com

Thanks to ACA...

The estimated 2 million children with pre-existing conditions who were uninsured before ACA passed are now eligible for coverage.

Lifetime caps have been lifted for 105 million Americans, including 28 million children.

Approximately 2.5 million additional young adults—including 1.3 million of racial and ethnic minorities—have already gained health insurance coverage since ACA passed.

54 million people with private health insurance—including 14.1 million children—have already received preventive care at no cost.

During FY 2011, more than 1.5 million children gained health coverage through Medicaid or CHIP,* bringing the total number of children enrolled in Medicaid and CHIP during 2011 to over 43.5 million. More than half of the children served by Medicaid and CHIP are children of color.

* Children's Health Insurance Program

Source: Children's Defense Fund



Ask the Expert

Elizabeth Stoltz
Group Manager, Reimbursement & Advocacy Team, Baxter's BioScience Business

Q: My employer offers healthcare, so my family is covered under that plan. I have questions about how the insurance policy works, but I don't want to call the number on the card, and I don't want to ask my employer. I'm worried that this would call attention to the fact that we have some expensive claims, and they'll want to drop our coverage. Where can I turn for help?

They probably know you're there. Self-insured employers do look at their costs. There are protections in the GINA (Genetic Information Nondiscrimination Act of 2008) law, so take a look online* if you have concerns.

Under the Affordable Care Act (ACA), often called the healthcare reform law, insurance companies cannot drop your coverage because of high dollar claims or if you have made a small mistake on your application. They *can* drop your coverage if you aren't paying your premiums, or if you've intentionally left something off your application that's a big deal—like the fact that you have a bleeding disorder.

I suggest calling the customer service line of your insurance company first.

Document the call! Take notes, with date, time, representative's name, and what you were told. Before you hang up, repeat back to the rep what he or she told you to make sure you've understood everything. Ask to get the information in writing too. It may also be helpful to speak to the social worker at your HTC or home care company if you're still uncomfortable asking your employer.

* Visit the website of the US Equal Employment Opportunity Commission at www.eeoc.gov and search "genetic nondiscrimination."



Q: Is it better to have a high deductible so I have lower premiums, or better to have higher premiums with a lower deductible?

You need to look at several things:

- How high is the deductible?
- Is there an out-of-pocket limit?
- Are your providers in-network? (Usually the copay or coinsurance is less when you use in-network providers.)
- What are the copays and coinsurances for healthcare services and medications (including factor) that you typically get?

Usually, the higher the deductible, the lower the monthly premium, because you're paying more upfront with a higher deductible. But sometimes, it turns out that the total amount you'll pay in premiums, deductibles, copays, and coinsurance is about the same, no matter which option you choose.

If that's the case, think about your budget. A high deductible means you have to pay more out-of-pocket at the beginning of your plan year. Do you have

some money saved to do that? If not, it might work better for you to have a lower deductible with higher monthly premiums. As you evaluate your options, make sure you look at all the care your family requires, along with the associated costs—not just the costs for the family member with hemophilia.

No matter what kind of deductible and premium you choose, remember that you'll need to have funds available to pay the deductible amount at the start of your plan year.

This can be complicated. To help you organize and make choices, speak to your HTC social worker. Also, NHF has posted some forms on its website. Visit www.hemophilia.org or call 800-42-HANDI for assistance. —E



Elizabeth is a group manager with Baxter BioScience's Reimbursement & Advocacy Team. She has worked in the healthcare industry for 20 years, and has been tracking healthcare reform since 2010. During her tenure with Baxter, she has educated chapters, individuals, HTCs, and specialty pharmacies on healthcare insurance. Elizabeth also helps the bleeding disorder community stay up-to-date on the effects of new laws.

Fighting for Insurance

Jo Schaffel

June 2011. David Smith*, 23, is graduating from college. A great milestone in anyone's life, especially for David, who has hemophilia. The Smith family is filled with pride, hope, excitement. Then, the letter comes. David has been taken off the Smiths' secondary insurance policy because he is no longer a student.

David's family is stunned. How could this be? Doesn't the 2010 federal Affordable Care Act (ACA) allow you to keep your children on your insurance policy until they turn 26?

The trouble begins

The Smiths, like many families, have two insurance policies. Their primary insurance covers the "normal" health expenses. A secondary, catastrophic insurance policy helps with their high medical bills. This secondary policy is offered through a professional organization that David's father, a doctor, belongs to. It was this secondary policy that was abruptly cancelled when David graduated.

"My office manager and I started calling the insurance company," Dr. Smith recounts. "Each time we called, we got a different answer." Several people at the company told him that the new law didn't apply to their catastrophic policy.

As time went by, Dr. Smith was getting frustrated and worried.

"This was really a problem, since our son's medical bills are substantial." He spoke to a supervisor at the company, and "she didn't know, either! Nobody there seemed to have a clue about the application of the law!"

After a few weeks, the Smiths were notified that their insurance company had decided not to cover David because, according to the company, their family's particular catastrophic policy did not fall under the new law. But Dr. Smith discovered that the company had elected to cover the clients who had a second, different type of catastrophic policy—one that required higher premiums.

Getting help

After about three months of getting nowhere, Dr. Smith thought, "Why not use the resources of National Hemophilia Foundation?" He called Michelle Rice, NHF's regional director of chapter services, for advice. After some research, she confirmed that under ACA, David could continue to be covered under his family's catastrophic policy until he turns 26 or has his own job-based coverage.

"So, in September, I wrote a very strong letter to my insurance company,"



says Dr. Smith. "This whole thing was becoming very stressful. We had to start borrowing some money to pay some medical bills. We usually pay off our credit cards in full, and we weren't able to do that during this time. I make a good living; what about people who aren't as fortunate?"

The Smiths also had to convert David to a different catastrophic insurance plan, with a separate premium, while they were waiting for him to be reinstated under their family plan.

Dr. Smith received no response from the insurance company. He waited a few weeks and made

Lessons Learned

- ❖ Don't give up
- ❖ Ask for help
- ❖ Have a backup plan
- ❖ Document everything
- ❖ Stay updated on the new healthcare reform legislation

*a pseudonym

continued on page 15

Community Forum

Q What resources are available to help bleeding disorder patients understand insurance reform? Where can they seek help if they have trouble paying for insurance?

Community Forum contributors represent unique perspectives and areas of expertise in the bleeding disorder community.



Michelle Rice
Regional Director for
Chapter Services,
National Hemophilia
Foundation

Several resources are available for people to learn more about healthcare reform, including the National Hemophilia Foundation website. Another helpful website is HealthCare.gov. This site is designed for consumer use, and does a good job of explaining the issues in easy-to-understand terms. For example, if you want to find detailed information on the market reforms that have already gone into effect (such as elimination of lifetime caps on essential health bene-

fits, or elimination of pre-existing conditions for children), the site has individual fact sheets, in both English and Spanish, that describe each reform. On this site, individuals and families can research the health coverage options available in their state, and can locate contact information for state agencies that are available to assist them, such as the Department of Insurance and Medicaid.

Patient Services Inc. (PSI) is a nonprofit with a 20-year history of providing assistance to chronically ill patients by subsidizing the cost of their health insurance premiums. For patients who qualify, PSI offers full assistance for one year. The amount of funding a client receives is based on several factors, including income, federal poverty level (FPL), and other extenuating circumstances. For more information, visit the PSI website or call 800-366-7741.

Finally, some states have state-funded hemophilia programs that provide assistance with unpaid medical expenses and insurance premiums.



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I depend on information from the NHF website, as Michelle mentioned, or the Hemophilia Alliance. Beth Sufian, a lawyer with Sufian & Passamano, operates the Bleeding Disorders Legal Hotline, a free hotline at 800-520-6154 (8:30 am – 5:00 pm CST).^{*} Patients can also contact their local bleeding disorder foundations; I rely on Hemophilia Foundation of Michigan. That said, HTC and chapters are often the best places to turn for assistance. A patient's social worker at the HTC is usually well informed.

After all other resources have been exhausted, PSI provides assistance if needed, or it may be possible via your local chapter to apply to the Helping Hands program through Hemophilia Federation of America. And patients can work out some financial issues and obtain guidance with their HTC social worker. Some chapters also have social workers to consult. These resources may help for short durations while a

^{*} The Bleeding Disorders Legal Hotline should be used only for questions requiring an attorney's perspective, such as discrimination/GINA laws, citizenship, and residency.



person gets back to work or is waiting for Medicaid or Medicare approvals.

Most of the pharmaceutical companies have developed free factor programs that patients can join while they have insurance; these programs provide factor during a lapse of insurance coverage or lack of insurance. Each one is different, so before joining, a patient needs to know exactly what the program offers: for example, how many units it will provide, and for how long.

There are still many questions about healthcare reform because (a) few of us are aware of what's in it to date, (b) we're not sure whether it will be deemed constitutional, and (c) we don't know yet how it will really shake out in action. Even as I write this, the overall message is, "Stand by for more information."

Jo Ann Volk

Research Professor,
Center on Health Insurance Reforms,
Georgetown University Health Policy Institute

Perhaps the best and most complete resource for all things healthcare reform is the website run by the federal government, HealthCare.gov. Patients can find simple explanations of the various reforms and when they go into effect, as well as more detailed, official documents like the law itself and the guidance or rules that have been issued. The website also helps patients learn about health coverage options in their own state (both private plans and publicly run programs such as CHIP and Medicaid).

Another resource was developed by Georgetown Health Policy Institute with

Community Catalyst, a consumer advocacy organization. The Health Insurance 101 website includes explanations of key private health insurance laws and terms, such as HIPAA, guaranteed issue, medical underwriting, and benefit standards.

Kaiser Family Foundation has a health reform website with a timeline and simple explanations of key reforms, as well as links to analysis, implementation updates from the states, and news updates. For state-specific information on insurance rules, healthcare program guidelines, and statistics, see the website StateHealthFacts.org.

Until 2014, patients who need help paying for insurance have limited options. HealthCare.gov includes state-specific information on programs for which eligibility is based on income (Medicaid and CHIP) and some state-funded programs for those who don't qualify for Medicaid (although these programs are few and limited in their reach up the income scale). Healthcare.gov also includes state

links to the Pre-Existing Condition Insurance Plan (PCIP) for uninsured individuals with pre-existing conditions. PCIP is not subsidized, but it may still be a more affordable option than other coverage for some people.

Beginning in 2014, federal financial help will be available to individuals and families with income up to four times the federal poverty level (about \$45,000 for an individual and \$92,000 for a family of four in 2012). Subsidies will be available only for coverage purchased through a state-based health insurance exchange that meets ACA guidelines. To help eligible individuals and families afford to buy insurance and get care once they have the plan, federal help will subsidize premiums and cap out-of-pocket costs (the total amount of copays and deductible). And with the ACA promise that no one will be turned down by an insurer because of a pre-existing condition, these subsidies will help almost 20 million people gain coverage by 2019. ↵

Experts' Picks

Resources for help with insurance questions

- | | |
|---|----------------------------|
| • HealthCare.gov | www.healthcare.gov |
| • Health Insurance 101 | 101.communitycatalyst.org |
| • Hemophilia Alliance | hemoalliance.org |
| • Hemophilia Federation of America (HFA) | hemophiliafed.org |
| • Kaiser Family Foundation (KFF) | www.kff.org |
| • KFF's Health Reform site | healthreform.kff.org |
| • National Hemophilia Foundation | www.hemophilia.org |
| • Patient Services Inc. (PSI) | www.patientservicesinc.org |
| • Pre-Existing Condition Insurance Plans (PCIP) | www.pciplan.com |
| • StatehealthFacts.org | www.statehealthfacts.org |



Brent

taught me how to be an advocate and empowered me by teaching me that we can make a difference especially when we work together and speak with one voice.”

Brent, who now practices law, also attended Washington Days annually for five years, and realized how the recent health reform implementations directly affected him. He believes that attending a legislative day, on either the state or national level, is a good way to learn the issues that affect our community.



Richard

Rich, a very active fellow indeed, has worked at hemophilia camps in several states and also served on NYLI. He became personally involved in legislation when he joined the staff of a US Senator. Rich puts it succinctly, “All opinions matter, and our voices play a critical role in advocating for these vital affairs.”

Nudge, Push, Shove—Mentors as Coaches

A mentor can be a stimulus to launch any new leader's involvement. Brent was first pushed by his nurse at his hemophilia treatment center (HTC) to get involved. Later, local community leaders influenced him.

But for young leaders, being in a new situation can be intimidating if they don't know what to expect, as Phil found out when he became a board member at NHF. Luckily he had a mentor, an experienced board member, who introduced him to others, taught

him how to read financials, and just helped him figure things out.

Mentors are our coaches. We can't run the race without their wisdom and experience—and a little push.

Practicing to Be Leaders

How can organizations provide opportunities for younger folks to participate, and even to lead? One strategy is to encourage young people to join a variety of events or committees suitable for them. Phil calls this giving new leaders “a seat at the table.” Rich points out that “youth programs and camps across the country are training the next generation of leaders in our community.” And these new leaders are having fun while participating.

Of course, when anyone new is learning the ropes, there's a chance that mistakes will be made; but the flip side is that the organization enjoys the benefit of new perspectives and insights. New leaders need an opportunity to learn and then to participate, by starting small and slowly increasing the responsibility. Significantly, all the young leaders profiled here—Brent, Pat, Phil, and Rich—attended hemophilia camp before becoming camp counselors themselves.

This is practice. Only through repetition is a skill honed and improved. Coaches, as well as our mentors, often remind us: practice makes perfect.

Leading from Personal Experience

Some of the greatest advocates in history learned powerful lessons from their own personal experiences. They learned from their own pain; they learned what worked and what didn't. By solving their problems, such as medical and insurance coverage, young leaders can then help others with the insights they've gained.

For example, Brent has undergone surgery several times and luckily, his insurance covered the procedures. Unfortunately, he had to change HTCs.

Now that he's older, Brent realizes that “obtaining a job with insurance is a great concern.” He shares this good advice with others.

Pat has similar concerns about health insurance coverage. He promises to “continue to work with my medical providers to make sure that I am covered and properly cared for as well.”

These personal experiences offer concrete examples of what patients must endure. Our personal challenges build our sense of compassion for others. The greatest leaders are often those who are compassionate, who empathize with the people they lead.

Passing the Baton

Brent, Pat, Phil, and Rich will continue in their leadership roles in state and national organizations. Some have been members of NYLI or similar groups, but that's not a prerequisite for leadership. As Phil says, “I have met so many incredible people in the hemophilia community with amazing talents, passion, and drive to leave this community a little better than they found it.” Pat, who envisions remaining in a leadership role, notes that enlisting leaders outside the bleeding disorder community from human relations and business is also vital: we need a variety of leaders with a range of perspectives.

Rich adds with insight, “I don't think leaders ever stop making the world a better place to live in, especially in the hemophilia community, because advocacy is naturally in our blood.”

We tend to feel better about ourselves when we join together with a common mission. And everyone benefits. With guidance, practice, and role models, we can continue to pass the baton of leadership—all for the goal of ensuring that the next generation of leaders in the bleeding disorder community will be properly prepared to advocate for health coverage. —

several more calls. After several more weeks had passed, he sent the company another letter requesting an explanation, in writing, of why David was not covered. He asked the company to quote exactly which parts of ACA allowed them to deny coverage.

He still didn't hear from the company. "We were getting the runaround," he says. "I wondered, was I being stonewalled? Or did the people at the company really not understand how the law pertained to them? Or was it a combination of lack of knowledge and stonewalling?"

Finally, Rice contacted an official at the US Department of Health and Human Services (HHS). "He [the official] made a phone call, and the very next day, I got a message from the insurance company that 'yes, you're right, you are covered,'" exclaims Dr. Smith.

Then...nothing for several more weeks. "I sent a few emails...nothing. I think HHS called again, actually," explains Dr. Smith. Then he finally got

a response. "The company said they were waiting...they had to draft a new policy with different language, and it had to go through the attorneys before they could issue it."

Seven months after David graduated and his insurance was dropped, the Smiths finally got word that his coverage was reinstated and all their claims since June would be reimbursed. "My gut feeling is that they got concerned when they realized the feds were looking at what they were doing."

"You just can't quit"

Dr. Smith has some knowledge of the insurance industry because of his work, and even he felt frustrated and defeated at times. He believes insurance companies often take advantage of people who may not be as savvy or organized as he is. "I'm an intelligent person with a lot of background knowledge in this area, and I had so much trouble! You just can't quit. They're counting on you to stop when they say no," he says, "or if they deny you for the second time, or if there's a long delay before they get back to you."

Dr. Smith believes his persistence paid off for other families as well. The supervisor at the insurance company told him that as a result of his complaint, the company had to change many other policies and reinstate a huge number of policyholders who had been dropped.

Fortunately, resources are available for the average person to get help with insurance issues.

NHF's website (www.hemophilia.org) has a section on insurance

and healthcare with information, updates, and contact information if you have questions or concerns. You can also share your insurance problems by filling out a form on the website.

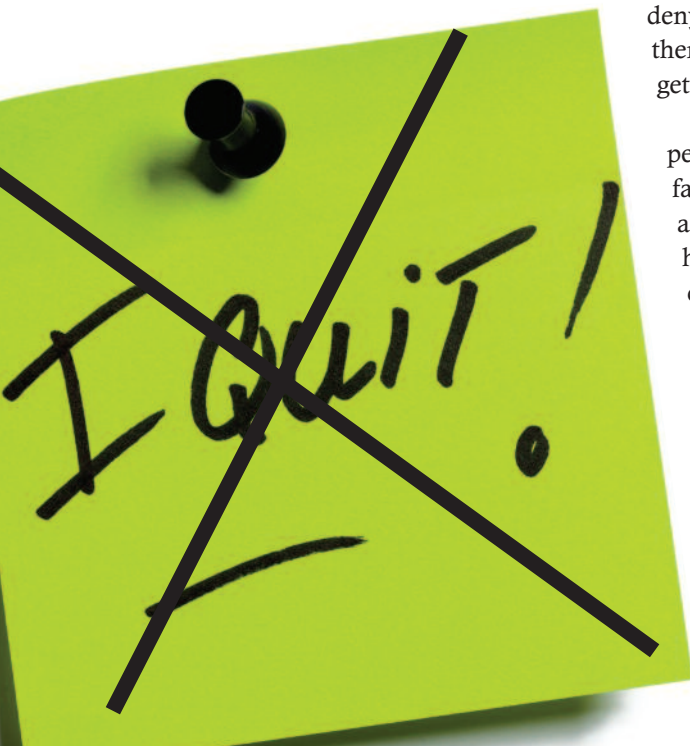
The federal government's healthcare website, HealthCare.gov, contains a lot of resources about health insurance in general, and information about ACA.

What does the future hold?

The Smith family is obviously relieved that this particular insurance ordeal is over for now, but they're worried about the Supreme Court decision on ACA that is expected this summer. "Will the court nullify the whole law?" wonders Dr. Smith. "Or just the mandate part? What will happen to my son's insurance? Will we have to pay back everything since the law took effect if it's nullified?"

He believes, "People with chronic illness in the family need some security." It's hard enough just to deal with medical issues that arise; the confusing state of health insurance in this country makes things more stressful. It's important to keep on top of what's going on in your policy, and reach out for help from individuals or organizations for support. Dr. Smith got a lot of help from NHF, and he urges others to reach out. "Anyone can call them to get help."

You can also contact your local hemophilia organization, HTC social worker, or other advocacy groups such as Hemophilia Federation of America. As Dr. Smith says, "It never hurts to get people involved to advocate for you." —



CARE (Coverage, Assistance, Resources, Education) Program

Inspired by listening to the community, Baxter created the CARE program to help members of the hemophilia community proactively manage their health insurance situations. CARE is open to all hemophilia A patients and inhibitor patients, regardless of current therapy or insurance coverage.

To enroll in the CARE program, contact your Baxter representative or call toll-free:
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