

PEN's Insurance Pulse

Inspiring Advocacy

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Healthcare Reform: What Happens to Hemophilia Now?

by Laurie Kelley

Republican Scott Brown's January election in Massachusetts was called "the Scott heard 'round the world," a wry reference to the shot, fired in Massachusetts, that began the Revolutionary War. Brown did what no Massachusetts Republican had done for 32 years — he won a senate seat.

This special election was to choose a replacement for Senator Ted Kennedy, who passed away in August. Brown's victory gave Republicans the extra vote they need to block the comprehensive healthcare reform bill in the Senate. A frustrating event for the Obama administration, which last year had proposed legislation in Congress to reform the nation's healthcare system.

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Welcome

PEN'S INSURANCE PULSE

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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 hemophilia. 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.

There's a lag time between an article's conception, research, writing, and publishing. We spend time on editing, proofing, layout, printing, and mailing. A lot can happen in a short time when something big — like national healthcare reform — is underway. By the time you read this, much more may have happened in Washington, DC, regarding healthcare reform.

So in this issue of PEN's INSURANCE PULSE, we decided to focus on the consistent concerns that affect healthcare for Americans with bleeding disorders. We've tapped into the opinions of key leaders in our community, who, despite a range of political and professional backgrounds, agree on what we *all* need in good healthcare reform. Though our country is increasingly divided along ideological lines, we are united as members of the bleeding disorder community. And our future is being determined right now in Washington.



We sincerely thank Baxter BioScience for sponsoring another issue of PULSE. Please read all the articles, share with family and friends, and get involved — by understanding the threats to your own healthcare policy, and by lending your voice to the national debate. The takeaway message: your individual voice truly thunders, all the way to the White House.

Laurie

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

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Transitions

“I Am Superman and I Can Do Anything!”

The Perils of Letting Your Insurance Lapse

by Kevin Correa

It's no big secret that many young men — with or without hemophilia — are endowed with an unwavering sense of invincibility. This can be a wonderful trait, allowing guys to push the boundaries of their comfort zone, and promoting self-discovery. But there's a downside: unnecessary risk-taking. And though it may not seem like the biggest gamble, letting your insurance lapse for even a brief time is a risk you should not be willing to take.

“Brian” is a 22-year-old with hemophilia. To say the college senior leads an active lifestyle would be a gross understatement. He has been a competitive swimmer and water polo player. He mountain bikes.¹ He rock climbs.¹ He backpacked Europe. You get the picture.

Like many young men with hemophilia, Brian has a general understanding of his insurance coverage and benefits, having dis-

cussed it occasionally with his parents. As a student, Brian is insured under their policy. But with graduation approaching and a tough job market awaiting, it may be some time before Brian finds a job that provides medical coverage. If he were to “age out” of his parents' policy, would he roll the dice and go uninsured, even for just a few weeks?

Brian chuckles at the question. *That's crazy.* “I'm not going to play games with my insurance coverage even if it's just for a month.” Brian has already started investigating the resources listed in the box at right for ideas on how to ensure coverage.

Unfortunately, not all young men make this wise decision.

Just 28 Days

“Walt,” a 22-year-old with hemophilia, was in a devastating car accident last October. He suffered injuries requiring several surgeries and an extended stay in intensive care.



Resources to Investigate

Though not a complete list, you may be able to tap into the following resources to avoid gaps in your insurance coverage. Because eligibility is not guaranteed, take the time to familiarize yourself with the requirements of any option.

Consolidated Omnibus Budget Reconciliation Act

COBRA was established to allow you to continue the insurance coverage you received through your employer during a time of job loss. The downside to COBRA is that it is temporary and expensive.

Public Assistance

All states have programs for people who can't afford medical expenses; several have assistance programs specifically for hemophilia. If you can't afford the high cost of COBRA coverage, you may qualify for a public assistance program like Medicaid or State Children's Health Insurance Program (SCHIP). And some states have high-risk insurance pools. But keep in mind that you may not qualify for these programs, even though you have hemophilia. Talk with your HTC social worker to learn more.

Other Alternatives

Patient Services, Inc. (PSI) is a nonprofit that helps people with chronic disorders by providing temporary insurance premium payments while they transition between policies. But remember that PSI is temporary. And depending on its funding level, PSI may not be able to accommodate everyone who applies.

Note: Although these resources are available, and you should explore them, your best strategy is to be proactive in maintaining or gaining primary insurance coverage.

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1. Always consult your physician before beginning any new athletic pursuits.

Healthcare reform offers sweeping changes and many promises, including better healthcare access, lower costs and medical insurance, and higher quality of care. Realistic? Possible? And at what price? The two bills — one in the House and one in the Senate — polarized Americans. The proposed reforms could have a deep impact on coverage for people with chronic disorders.

Looking beyond bipartisan politics, what aspects of the healthcare reform bills will most affect people with bleeding disorders? What do you need to watch closely, regardless of your political affiliation?

Why Healthcare Reform Now?

The latest push for national healthcare reform was initiated by Democrats last year. The goal was to provide accessible and affordable health insurance options, especially for most of the 46 million Americans lacking insurance.¹ With a Democrat in the White House, the time seemed right for reform. Efforts were massive: this was the largest healthcare undertaking by the government since the introduction of Medicare and Medicaid in 1965.²

But the urgency and scope of reform proposals raised red flags. Conservatives are wary, believing that government should be less involved, not more involved. Still, everyone agrees on one thing: too many Americans are without health insurance, and health costs are rising astronomically. The question is how to fix the system.

"The purpose of legislation was *not* to create a new, national health insurance plan like those in Canada and Europe," says David Linney, a

private consultant. "Rather, it was to fill in the gaps in our current system."

These gaps are found in oft-cited statistics: despite the best medical facilities and healthcare in the world, we lag behind on many health indicators. Life expectancy at birth in the US is an average of 78.14 years, ranking 47th compared to other countries. Our infant mortality rate ranks 43rd, lower than Slovenia and Cuba.³ The people who need healthcare the most — the chronically ill — are burdened with heavy costs, and even people with insurance can become bankrupt.

But it's the cost of healthcare that has raised the most alarms. In what is mainly a free market system for healthcare, US healthcare costs are the highest in the world, and still rising. Kaiser Family Foundation reports that from 2000 to 2006, overall inflation increased 3.5%, and wages increased 3.8%, but healthcare premiums increased a whopping 87%. The number of expensive specialty drugs,

including biologics like factor concentrate, is exploding. Kaiser Family Foundation calculates that over the past 15 years, a large part of the growth in healthcare costs was due to drug costs.⁴ And almost half of all healthcare spending was used to treat a mere 5% of the population, including those with chronic diseases like hemophilia. According to Doug Stratton, director of the Indiana Comprehensive Health Insurance Association and past chairman of the National Association of State Comprehensive Health Insurance Plans, "We need to discuss the foundation of the problem: yes, access and quality of care are issues, but the reason this has become a crisis is due to costs. Pure and simple."

America's Affordable Health Choices Act of 2009 sought to rein in costs, and to get Americans insured. The bill would have required 97% of Americans to be covered by either private or government administered health insurance by 2015. It proposes a public health insurance option called an *exchange*, which would allow individuals and businesses to shop for health insurance. Would this save money in healthcare costs, or cost us more money in debt and higher taxes? In July the nonpartisan Congressional Budget Office (CBO) estimated that implementing the Health Choices Act will cost more than \$1 trillion and add \$239 billion to the federal deficit by 2019. Americans drew battle lines about whether this makes good fiscal sense.

In the aftermath, it's back to the drawing board. National Hemophilia Foundation (NHF), Hemophilia Federation of America (HFA), and Committee of Ten Thousand (COTT), our watchdog groups, are waiting. But they continue to advocate for reform.



1. According to the US Census Bureau's website, of the estimated 46 million "Americans" without health insurance, more than 10 million are non-US citizens. 2. Tumulty, Karen, "Dems Brace for the Hardest Part of Health-Care Reform," *Time*, Oct 5, 2009. 3. *CIA World Factbook*, 2008. www.cia.gov/library/publications/the-world-factbook 4. Kaiser Family Foundation. www.kaiseredu.org

Michelle Rice, mother of two with hemophilia and NHF regional director of chapter services (point person for state advocacy), says, “My fear was that legislators would say, ‘Forget it, let’s just start all over.’ NHF is encouraging families to contact their representatives and senators and say, ‘We want you to keep moving forward with health reform, and let us tell you what’s important to us.’”

NHF and leading advocates in the bleeding disorder community have analyzed what can and should survive in a future bill to help those with chronic disorders — regardless of political leaning. Here’s what you need to know:

1. Lifetime Caps

Lifetime maximums, or caps, should be the primary concern in any healthcare reform bill for families with chronic disorders. Caps place a limit on total individual healthcare expenses in private insurance over a lifetime. Payers use caps as a way to limit spending by enforcing, in effect, a budget. Some caps are \$1 million, some are \$5 million. A Kaiser Family Foundation survey found that the trend of insurers using caps is rising: 55% of employees had a lifetime limit in 2007, including 23% with a cap of less than \$2 million. That’s up from about 50% facing a cap in 2004.⁵

With hemophilia patients using an average of \$60,000 to \$200,000 per year in factor costs alone, a \$1 million cap doesn’t last long. When a cap runs out, then what? Patients and families must either look for another policy, find a new job with a new policy, or investigate government assistance. One way or another, taxpayers are left footing healthcare bills.

Andy Matthews, 44, a Texan with hemophilia, speaks frequently about insurance, particularly to audiences of

**Bleeding Disorders
Legal Information Hotline
800-520-6154**



young men. “One of the misstatements I hear all the time is that everyone with hemophilia thinks that if I lose my insurance, I can get on Medicaid and Medicare,” he says. “But it’s not that simple. It’s getting harder to qualify.”

Eliminating lifetime caps would have an immediate impact on people with bleeding disorders. No one would be forced to change jobs or alter their treatment regimen because they fear exceeding an insurance cap. And, notes Rice, “There is bipartisan support for the elimination of lifetime caps. There is just disagreement on how to accomplish it.”

One caveat: if a healthcare reform bill eliminates lifetime caps, it may include *annual caps*. An annual cap limits the number of healthcare dollars that can be spent in a calendar year. So although you may have unlimited dollars to spend on hemophilia care over your lifetime, you would be limited each year. Annual caps are one piece of

reform that bleeding disorder advocates want to eliminate.

2. Pre-existing Conditions

One way to keep costs down and increase profits is to drop the “expensive people” from insurance policies. The first targets? Patients with a known disease or disorder when they purchase insurance coverage — a pre-existing condition. If you have hemophilia and want insurance, the insurance company already knows that you’re going to cost a *lot* of money.

So insurers can discriminate against certain patients. If you have a pre-existing condition like hemophilia, this can mean you’ll wait six months to a year before the insurer allows your policy to cover any costs. Sometimes it means no policy at all. In most states, insurers are not obligated to offer you a policy if you have a pre-existing condition. And if they do, they can raise your premium higher than the premiums of healthy people. Insurers can also exclude coverage only for your particular condition.

“There is little state or federal regulation,” adds Dana Kuhn, a person with hemophilia and president of Patient Services, Inc. “What we really need in any healthcare bill is elimination of the pre-existing waiting periods for all insurance policies. This means protection of *guaranteed issue* policies; these kinds of policies give you immediate coverage regardless of your medical history.”

3. Affordability

If healthcare reform eliminates both lifetime caps and pre-existing condition clauses, there needs to be a source of revenue to pay for the resulting increase in medical expenses. Rice calls these “market reforms,” and to pay for

5. Lee, Christopher, “More Hitting Cost Limit on Health Benefits Consumers Forced To Explore Options,” *Washington Post*, Jan 27, 2008.

them, she explains, “insurers will most likely have to increase premiums. So you may get access to healthcare, but that’s only half the issue. Can you afford to get it?” Rice notes, “One of the issues facing Congress is how to make reform affordable. One suggestion has been to *require* everyone to have health insurance. This would expand the risk and help keep costs down. Other suggested cost containment would be in the form of taxes.”

If premiums rise as a result of healthcare reform, who will pay for them? The same people who pay now: employers. Employer insurance costs have been rising; further increases will force employers to shift some cost to employees. What then? Individual out-of-pocket costs will go up. Or employers will raise the cost of their goods and services to the US market. What then? Inflation.

Matthews wishes that he “could just go out and buy my insurance with-

Did You Know?

For the past 20 years, PSI has helped hundreds of thousands of chronically ill people afford the high cost of health insurance premiums and co-payments nationwide.

Did You Know?

Only \$6,000-\$15,000 of assistance stands between a family with a chronic illness and bankruptcy? PSI is the safety-net to helping avoid this.




How Can PSI Help?

Are you challenged with COBRA payments? Do you need help locating health insurance? PSI can help you. Simply call (800) 366-7741.

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out the high premium. If I could get my policy at the same price as anyone else, even \$700 a month would be doable, and it would help so much.”

Kuhn agrees. “The main thing is affordability. The House and Senate bills could do this — limit the amount that a payer could charge for a premium. That’s what the public option is supposed to do. If people don’t like what a private insurer is charging, they could go to a public option and get a cheaper policy.”

Affordability is crucial for people with bleeding disorders and includes not only lower premiums, but other kinds of reduced costs. Rice notes, “There also needs to be a limit on out-of-pocket expenses. Or maybe some type of credits or subsidies to help lower-income families afford these policies.” People with bleeding disorders often pay out-of-pocket costs (sometimes called OOP) when they order factor, and for many, these costs are rising. Kuhn points out, “The House bill was trying to limit out-of-pocket expenses; the Senate bill *did* limit them.” Without reform, he predicts, out-of-pocket costs may continue to rise.

One Solution

The healthcare reform bills propose one way to lower costs: a public option, funded by the government, whose purpose is to create competition with private insurers, forcing more affordable premiums. The public option would be open to Americans who lack adequate coverage from their employers, and to employees at small businesses, with fewer than 20 employees. And it would be available through an exchange, over state lines, so people could obtain both private health insurance plans and the new public option. Someone in Texas could shop for a better and more affordable policy in Utah, for example. An innovative idea, because the insurance industry is largely unregulated. And a controversial one.

Kuhn believes the public option would serve the bleeding disorder community well, by reducing the costs of premiums and allowing people to shop across state borders. “Virginia once had a health mandate to cover hemophilia health costs, but not the cost of product. If that were to happen under a public option, we would be able to use the exchange, and shop for a better insurance policy in a different state. That’s not possible now.”



COVERAGE • ASSISTANCE • RESOURCES • EDUCATION

Baxter's CARE Program: Be Proactive with Your Health Insurance

The CARE program is a new comprehensive insurance assistance program from Baxter BioScience, designed 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 CARE, contact your Baxter representative or call toll-free:
1-888-BAXTER9 (1-888-229-8379)

Stratton notes, “There needs to be separate funding for extraordinarily high-cost cases. Currently 35 states have initiated or are implementing high-risk programs. The most appropriate course to pursue is to have the federal government commit adequate resources to fund high-risk plans, and assist them in creating programs to address the extraordinary cost of those with the most expensive conditions.”

The Cost of Inaction?

Healthcare premiums are rising by double digits every year. Medicaid is overburdened in every state, and most states are running deficits. The number of uninsured Americans is growing. Healthcare represents the single largest US budget item, the highest percentage of GDP (gross domestic product) in the world.

Everyone knows that something must change, but as a nation, we can't agree on how and what to change.

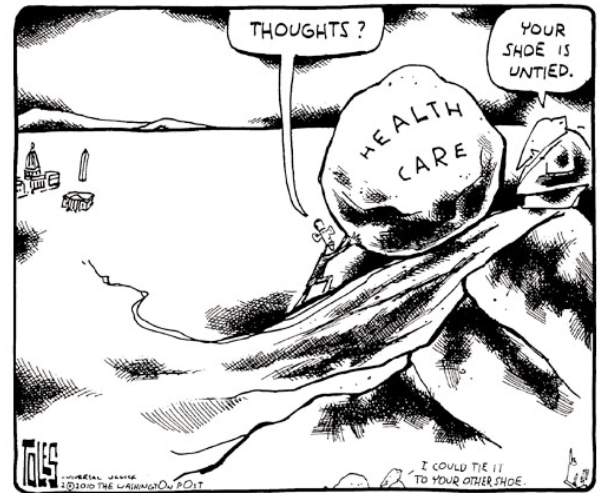
“There's a chance that the areas that affect those with bleeding disorders, like caps, might be reformed this year,” says Matthews. “When legislators go back to the drawing table, I hope they say, ‘Let's do the little stuff that makes sense first.’ We also need to look at this in a much bigger picture: healthcare reform must be seen in the context of the national debt, for example. If our country goes broke, none of this will matter.”

Kuhn predicts, “If we don't make health insurance accessible and affordable, get rid of pre-existing condition restrictions and caps, and make coverage immediate, the healthcare system will crash in two to three years. It will become a luxury that most will not be able to afford — a luxury, not a right. Hospitals will not be able to take on the debt of the uninsured.”

Federally funded hospitals cannot turn patients away, no matter what their financial situation. This can cause massive debt, especially if they are hemophilia patients without insurance. Kuhn believes that the burden on HTC's will drive hospitals into debt, forcing up taxes — with taxpayers footing the bill. And returning to the ER would be a step backward in hemophilia care.

“This is what I say when I visit members of Congress,” Kuhn shares: “It will cost money to reform healthcare, but would you rather pay \$6,000 for a premium, or would you rather pay a \$22,600 average for one five-day hospital bill? And that's without factor.” In November the CBO estimated that a revised healthcare reform bill would yield a net reduction in deficits of \$138 billion over ten years, though many members of Congress do not accept this.⁶

Rice predicted that something would pass this year, perhaps a watered-down version of the current bills. “If we do nothing,” she warned, “we'll see more and more people uninsured, with healthcare costs continuing to rise along with insurance costs and premiums.” Hemophilia is already on the insurers' radar screen; they already are restricting choice of factor provider. They may attempt to limit product choice to one product. There may be more insurer-owned specialty pharmacies, where insurers can exert more control. Rice adds, “The standard of care that we know now may start to suffer.”



2010 Toles © Washington Post. Used by permission. Universal Uclick. All rights reserved.

The crucial question: what is the cost of inaction? “Do I want to help shape what's happening,” asks Rice, “or sit back and react to the negative impact on me later?” At NHF, she stresses, “We believe it's important for the bleeding disorder community to voice their concerns to help ensure that their needs are addressed in any reform that occurs. And based on the number of people attending this year's Washington Days — 350 strong! — it seems the community agrees.”

Stratton urges, “The most effective thing people can do is to write to their congressional representatives. People know that, and some choose not to do it. But it does have an impact!”

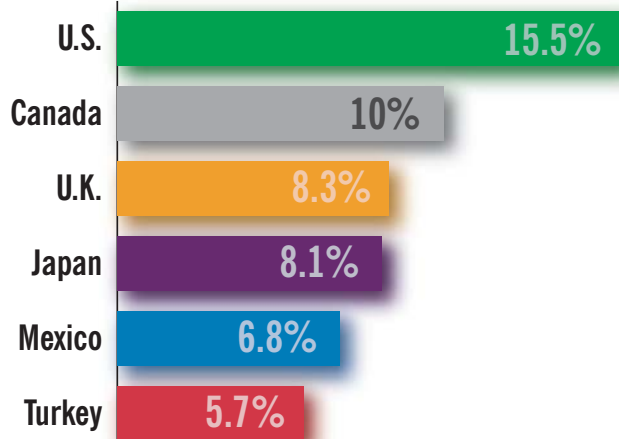
Change is inevitable, it seems, regardless of whether we support the current initiative to reform healthcare. All of us who live with bleeding disorders will need to read more to stay current. And patients and parents may decide to get involved locally or nationally in the debate over healthcare reform, so that as change happens, it is change our community can live with and afford — both now and in the future. —

6. H.R. 3962, Affordable Healthcare for America Act, Nov 20, 2009. www.cbo.gov

Tracks & Trends

US Healthcare Most Expensive

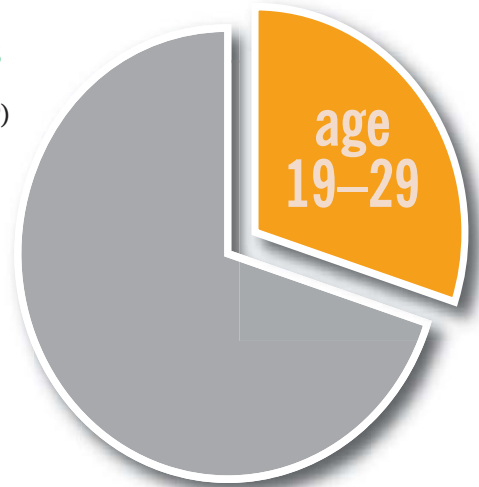
Healthcare expenditures as % of GDP



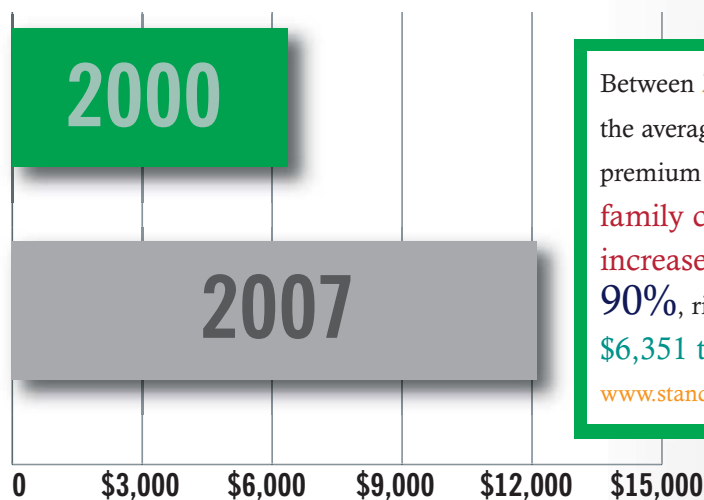
Organization for Economic Cooperation and Development, OECD Health Data (Paris OECD, 2008)

Risky Business

Young adults (age 19–29) have the **highest** uninsured rate of any age group in the US, representing **30%** of the overall uninsured population.



Schwartz, Karyn, and Tanya Schwartz. 2010. "Uninsured Young Adults: Who They Are and How They Might Fare Under Health Reform" Kaiser Commission on Medicaid and the Uninsured. www.kff.org



Between 2000 and 2007, the average health insurance premium for an employee's **family coverage** **increased** by more than **90%**, rising from **\$6,351** to **\$12,106**.

www.standupforhealthcare.org



Eight manufacturers are now **licensed** to **sell** hemophilia products in the United States.

In **25** states and in the District of Columbia, **insurers** can dig through at least a year of **your** **medical history** to find out if you have a **pre-existing** condition.

www.standupforhealthcare.org



How big is a billion?

One of the proposed healthcare bills is estimated to add **\$239 billion** to the federal deficit by 2019.

If a billion kids made a human tower, it would rise above the moon.

If you counted from one to one billion, you'd be counting for 95 years.

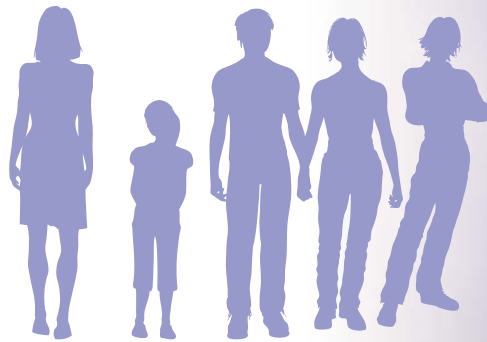
If you found a goldfish bowl large enough to hold a billion goldfish, it would be as big as a football stadium.

Schwartz, David M. *How Much Is a Million?* New York: HarperCollins, 2004.

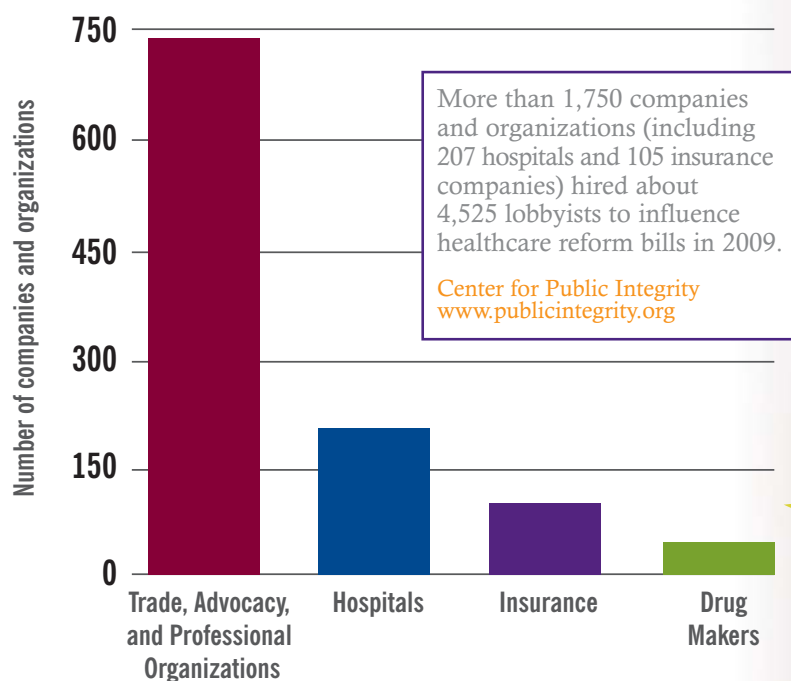


Four of five uninsured Americans are in working families. **One of five** uninsured Americans is a child.

www.standupforhealthcare.org



Eight Lobbyists for Each Member of Congress



According to the Centers for Medicare and Medicaid Services, the US is projected to have spent over **\$2.5 trillion** on healthcare in 2009.

Ask the Expert

by Mike Bradley

Vice President of Healthcare Economics and Reimbursement, Baxter BioScience

**Q: If I am currently unemployed, can I get an extension of my COBRA eligibility? Is additional payment assistance available?**

Yes, you can get an extension. Since 1985, employees have had a safety net with COBRA, a federal government program that allows people who have either been laid off or otherwise unemployed to continue their employer-sponsored insurance coverage for up to 18 months. The federal government mandates that large employers (employing 20 or more people) must offer COBRA to their eligible employees. If you don't work for a large employer, it's important to check with your employer for any similar continuation coverage, or as many states call them, "mini COBRA" plans. Your state's department of insurance is another resource when investigating these continuation provisions.

Until recently, the cost to continue coverage was out of reach for many people. Employees were responsible for maintaining the full insurance premium — the employee's and employer's shares, plus fees. That's an average cost of \$1,137 per month for families and \$410 per month for individuals.

This changed with a temporary government boost in 2009 through the American Recovery and Reinvestment Act (ARRA). Under the new COBRA extension, employees who are out of work and are eligible for COBRA now have a 65% subsidy for their premiums for up to 15 months. This provides a much more manageable average premium of \$398 per month for families of three or more, and \$144 per month for individuals. With this extended COBRA subsidy from ARRA and the December 2009 extension in the Department of Defense Appropriations Act (H.R. 3326), more people who have lost their jobs now have options.

To be found eligible for this subsidy, individuals must experience a COBRA qualifying event, which includes involuntary termination of a covered employee's employment. The involuntary termination must have occurred during the period that began September 1, 2008 and ended February 28, 2010. The premium reduction applies to periods of health coverage that began on or after February 17, 2009, and lasts for up to 15 months. Visit www.dol.gov/ebsa/faqs/faq_consumer_cobra.html to learn about qualifying events.

And yes, additional payment assistance is available. Patient Services, Inc. (PSI) helps people with hemophilia and other conditions by subsidizing the cost of premiums, including those associated with COBRA, state high-risk pools, open enrollment, and other special circumstances. To learn more about PSI's assistance programs: www.uneedpsi.org or 800-366-7741.

Q: If I move out of my parents' home, do I need to get my own health insurance coverage? How do I find out if I am still covered under my parents' policy?

It depends. You may lose your parents' insurance when you turn 19 and you're not in school. Many private insurance policies will cover young adults for a longer period if they are attending school full time. Even if you're still in school, your parents' insurance coverage may stop when you reach age 23.

Most low-income young adults are

not currently eligible for Medicaid or the Children's Health Insurance Program (CHIP). When they turn 19, their coverage normally terminates because adult eligibility for Medicaid is much more limited. As a result, only 13% of all young adults aged 19–29 have public coverage, compared to 31% of all children.

Twenty-five states have increased the age at which children can be covered under their parents' private health insurance plan in the group insurance market. Many states increased the dependent age to 25, while other states chose age 24 or 26. Most state laws apply to all young adults, but the laws in several states apply

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Living in Insurance Limbo

by Sara P. Evangelos

Martin Addie faced an insurance crisis: he hit the \$2 million lifetime maximum on his employer's health plan, and then capped out on a state high-risk plan. Now he is close to capping out on his wife's plan. So Martin consulted his employer, his insurance company, his hemophilia organization, his legislators, and his friends in the bleeding disorder community. But he still couldn't find enough health insurance to cover his medical needs.

Martin, a priest in the Church of Christ and assistant pastor in Springfield, Missouri, has severe hemophilia A. In a single year, his hemophilia-related medical costs average \$300,000.

"Maintaining health insurance has been a lifelong struggle," admits Martin. In 1984, he landed his first job with health benefits: working for the city of Springfield. When Martin reached his \$1 million cap in the mid-1990s, the city raised the policy's lifetime maximum to \$2 million to meet his needs, and also for all employees on its self-insured program.¹ But when Martin capped out again in 2002, the city would not raise the maximum a second time.

"If the 24-month waiting period for Medicare was removed, or insurance caps were outlawed, millions of people could get on with their lives."

—Martin Addie

Because he had capped out, Martin could now qualify for a high-risk plan under the Missouri Health Insurance Program (MHIP). "I applied and was accepted," he recalls. "But I maxed out the high-risk \$1 million cap in 47 months."

In July 2006, Martin was accepted on his wife Janeen's insurance plan. By September 2009, he had used nearly 90% of the \$1 million cap. In 2008, Martin's surgeons recommended elbow, shoulder and knee replacements. He didn't have enough insurance to cover the projected factor costs, so the surgeries were not performed.

His health challenges increasing, Martin applied for social security disability, and payments began in May 2009. He then retired on his social security disability, plus a disability pension after working for nearly 30 years. But because of Medicare's 24-month waiting period, his Medicare coverage won't begin until May 2011. Martin knew his current insurance would max out in less than a year.

Was Medicaid a possibility? "To apply for Medicaid," Martin explains, "we'd have to become indigent and dependent on the state. We have too much income to qualify for many programs, but nowhere near enough to pay for my own care until Medicare is available."

Martin was in insurance limbo, unable to find medical coverage, and months away from qualifying for Medicare. "I didn't know what I would do for coverage after I capped out



Janeen and Martin Addie

again, and before Medicare began," he says. "I might get assistance from compassionate care plans through home care providers or manufacturers, but that wouldn't cover blood tests, doctor visits, new medications, an ER visit, or a hospital stay."

Martin tried everything. In fall 2008, he asked Janeen's employer to consider raising the maximum on its own self-insured plan. He was told not to appeal until he capped out, so he appealed in December 2009, but was denied.

Martin learned that an income-based Missouri program would pay only about \$9,500 per year. To raise awareness, he approached his local and federal legislators, and published an editorial describing his insurance dilemma.

Unfortunately, the MHIP high-risk plan would not accept Martin a second time. And he learned that the 24-month waiting period, from the start of social security disability until his Medicare benefits begin, can be waived only for two specific conditions — hemophilia not among them.

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1. A self-insured program is a health insurance plan owned by the company itself and usually administered by a third party, such as an insurance company.

Community Forum

Q Even as the healthcare reform bill is being reworked, what parts of it will most benefit patients with bleeding disorders?

Community Forum contributors represent unique perspectives and areas of expertise. Surprisingly, in answering our question for this issue of PULSE, they all emphasize similar points about healthcare reform legislation and its impact on the bleeding disorder community. And they all urge the community to remain proactive and informed as healthcare legislation evolves.



Kisa Carter

Public Policy Director,
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Federation of America

Over the past year, healthcare reform legisla-

tion has received numerous modifications. Crucial components of the bills are reflected in both the House and Senate *provisions*, or conditions, many of which modify the insurance market. Several key provisions remain that will tremendously benefit the bleeding disorder community.

Lifetime and annual limits on health insurance plans pose challenges for many families throughout the United States. The bleeding disorder community advocated for many years to eliminate lifetime caps. The provisions that eliminate lifetime and annual limits on health insurance plans are a positive step, although fine-tuning must take place before final passage of a bill. A thorough provision should eliminate lifetime and annual limits in *all* plans, both new and existing.

An equally important provision would prohibit the ability to discriminate because of a pre-existing condition. People with bleeding disorders and their families continue to face discrimination because of their medical history or condition. Generally, the provisions seek to prohibit pre-existing condition

exclusions in most markets — individual, small, group, and the possible insurance exchange.* To be effective, healthcare reform legislation must prohibit pre-existing condition exclusions in *all* markets.

The provision that places caps on the dollar amount that families pay in out-of-pocket costs will benefit the bleeding disorder community. Out-of-pocket costs can financially ruin an individual or family with an expensive disorder. Congress must set a dollar limit, as opposed to caps that are set based on percentages.

A comprehensive overhaul of the current system can provide true benefits to the community. What we know today is that numerous components of the health insurance and healthcare system are unfavorable to people with bleeding disorders. The proposed changes, such as the elimination of lifetime caps, can protect and promote continued access to quality, affordable care, and safe therapies.

* See p. 4, feature article.



Jed Perry

Director, Federal
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Baxter Healthcare
Corporation

While debate over the path

forward for comprehensive healthcare reform continues, people living with bleeding disorders would do well to

closely follow discussions on a key element of the proposed legislation: health insurance reform.

Under our current healthcare system, people with bleeding disorders face numerous challenges to keeping and maintaining health insurance. As patients transition from one job to another, or as children “age out” of their parents’ insurance, insurance companies may deny or limit coverage because of pre-existing conditions. People with bleeding disorders who do have health insurance may also find themselves reaching both annual and lifetime benefit limits while treating their condition. Any of these circumstances that alter insurance status could cause significant gaps in coverage, which often force many to obtain care through Medicaid or other safety-net providers, or worse, to go without care.

The healthcare reform measures passed by both the House and Senate late in 2009 include provisions to restrict insurance companies’ ability to limit coverage for patients. Specifically, the bills eliminate insurance companies’ ability to deny or limit coverage for patients with a pre-existing condition. And the bills significantly limit or eliminate annual and lifetime caps over time. These two elements — pre-existing condition and the elimination of caps — most benefit patients.

Unlike some of the more controversial, and potentially problematic, policy reforms contemplated in healthcare reform, elimination of pre-existing conditions and annual or lifetime caps enjoys support from both Republicans and Democrats. If Congress passes a limited version of healthcare reform, many believe that these insurance reform issues should be included. The challenge is that, although widely supported, both policy changes could result in higher insurance premiums unless all Americans are required to purchase health insurance. Such a mandate, and the financial subsidies necessary to help low- and moderate-income Americans afford the premiums, remains a debated issue.

Given the existing political landscape, it is extremely important for everyone in our community to work to protect the standard of care available in the United States. Staying informed on healthcare reform issues and being involved in shaping the debate are vital to ensure that people living with bleeding disorders and the appropriate management of their healthcare will be fairly represented.



Kate Muir

Chair, New England
Hemophilia Assoc.
Advocacy Comm.
Board of Directors

The bleeding disorder community

has been concerned about healthcare reform for decades, well beyond the recent several months when legislation has been stalled in Congress. Since the earliest efforts to establish the federally funded HTC network — a vision to secure expert diagnosis and state-of-the art treatment for

families throughout the country — we've been discussing two key issues: *access* and *cost of care*. As we have become more autonomous through increased knowledge, self-infusion, and the benefits of home care, the responsibility of advocating for our healthcare needs has never been more crucial than now.

I believe we should have little room, or patience, for political posturing in the national discussion of healthcare reform. The incidence of bleeding disorders crosses all cultural, social, economic, geographic, and ethnic boundaries. Access to affordable, quality healthcare is a unified need and challenge, regardless of political affiliation. For people living with expensive lifelong chronic disorders, it's inexcusable to place so much emphasis on partisan tactics that delay the effective, productive dialogue needed to shift the direction of our nation's healthcare crisis. There is work to be done.

The three bills (two in the Senate, one in the House) resulting after months of consideration and research have much in common that could potentially benefit the bleeding disorder community. The historic expansion of Medicaid proposed in each will benefit all low-income individuals, not just select groups. Each bill proposes significant cost savings for Medicare. Each bill agrees to implement more uniform practices regarding the coverage of pre-existing conditions and other restrictions based on diagnosis. As the dust settles around the public option uproar, it's clear to me that a public option should be retained, in some limited format, to provide coverage for individuals who do not qualify for Medicaid, want to keep their jobs, but don't have access to affordable coverage through their employer.

Our legislators need to develop con-

sensus in finding the least costly and most comprehensive approach to pay for the program if it passes. Without clear indications that the overall impact will be to lower national medical spending or insurance premiums, the question of cost may be the greatest challenge of the entire process. To the bleeding disorder community, the alternative of doing *nothing* is unacceptable. So we must encourage and support all of our legislators, on both sides of the aisle, to get the job done on healthcare reform.

Our son will graduate from college in June. He has become his own best advocate in managing his hemophilia. He's well aware of the cost of his care and the need for adequate insurance. With the personal and macroeconomic future of hemophilia so uncertain, it's unfathomable that today, our community's greatest challenge transcends biotechnology and individual perseverance — and is now economic and political immobility.



David Linney

Consultant,
David R. Linney Inc.

The initial proposed legislation would have in time eliminated

the problem of someone being denied insurance coverage because of a pre-existing medical condition like hemophilia. It would also have minimized the wait time for pre-existing condition exclusions, that is, the period that a person may have to wait before the medical condition is covered.

Dependent coverage was also to be extended until age 26 or 27. Removal of annual and lifetime limits was

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Just before the accident, Walt had left a job and was slated to start a new job one month later. Anticipating only a short gap in his insurance coverage, he was uninsured at the time of his accident.

Given that the cost of his factor alone likely exceeded \$10,000 a day, it's easy to see how an extended hospital stay like Walt's can be financially crippling.

Medical bills like Walt's are the reason that about half of all personal bankruptcy filings in the United States are attributed to medical causes.²

It Won't Happen to Me

If you're Mr. Invincible, the mantra echoing in the back of your head is probably this: *It Won't Happen to Me*. But the truth is that if you suffer an injury requiring medical treatment at any point in your life, it's more likely to occur between ages 15 and 24 than during any other 10-year span of your life.³

Sure, a car accident like Walt's is relatively rare. But not every hospital visit is the result of some mishap. Take appendicitis: according to the National Institutes of Health, although anyone can get appendicitis, it occurs most commonly in people between ages 10 and 30, and compared to any other cause, it results in more emergency abdominal surgeries.

The cost for an appendectomy varies widely. In Florida, for example, the price range is between \$24,000 and \$41,000 for the average hospital stay of 2.5 days.⁴ That price does not include the cost of factor, which could tack on another \$25,000 to \$30,000.

If you don't have insurance, your case will be reviewed by the hospital's financial screening department to determine what

portion of your bill you have to pay. Danna Merritt, social worker at Children's Hospital of Michigan, cautions, "Unless you can prove a hardship, you will be asked to pay at least a portion of the bill." Keep in mind that you and the hospital probably define *hardship* differently.

The point is that although maintaining your medical insurance may be expensive, you really can't afford to risk going without it.

Of Critical Importance

Dana Kuhn, president and founder of Patient Services, Inc. (PSI), believes that the hemophilia community has to do a better job of impressing upon teens the value of maintaining their health insurance. "It's critical that we educate [young men] and help them better understand how important health insurance is to people with bleeding disorders," says Kuhn. "And it takes a lot of good counseling to adequately prepare them to come of age."

Merritt agrees. "We begin talking about insurance with young men at age 15." Due to the complex nature of insurance coverage, Merritt doesn't limit the discussion to her patients. "We do our best to educate Mom and Dad so the family can prepare for insurance changes together."

Even if changes in insurance coverage seem to be years away, speak with your HTC team to develop a contingency plan in case you have an unexpected lapse in coverage. As Merritt wisely advises, "It's much better to understand your options *before* you have a problem." ✦

Readers may recognize the lyrics from the song "Superman" by R.E.M. in our title.

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addressed, but there was a lack of agreement about when and how the elimination of limits would affect new and existing plans.

So what does this mean for the bleeding disorder community? It means that we can be hopeful for legislation, but as of now, we still have to deal with the same insurance issues and maybe a couple of new ones.

Any legislation that is passed will help all citizens, particularly those with chronic conditions. Legislation that would eliminate pre-existing conditions, lifetime limits and annual limits would especially benefit people with bleeding disorders, and we should continue to advocate for these.

The two "new" problems for the bleeding disorder community are increased out-of-pocket costs and the possibility of more health and drug plans imposing annual limits. An annual limit imposes a dollar limit on how much an insurance plan will pay for medical or drug costs in a single year. When that limit is reached, there is no coverage for factor product costs until the following year. As healthcare inflation increases, more insurers may impose annual and lifetime limits to control costs. Because of this possibility, the bleeding disorder community should carefully monitor annual and lifetime limits in the marketplace.

Regardless of what happens with healthcare legislation, health insurance premiums and out-of-pocket costs will continue to rise. Increased costs pose a problem for all consumers, but more so for people with expensive medical conditions. As costs continue to rise, coupled with our down economy, it will be harder for many people with bleeding disorders to keep up with medical bills. ✦

2. Himmelstein, David U., Elizabeth Warren, Deborah Thorne, and Steffie Woolhandler, "Illness And Injury As Contributors To Bankruptcy," *Health Affairs*, 2005. DOI 10.1377/hlthaff.W5.63. 3. Centers for Disease Control and Prevention, *Surveillance Summaries*, September 3, 2004. MMWR 2004;53(No. SS-7). 4. Florida Agency for Health Care Administration. Figures represent average low and high charges.

Martin explored all his options, including having Janeen change jobs or relocating to another state. “I’m able and willing to pay reasonable premiums,” he stresses. But because of his pre-existing conditions, “the problem is finding any insurance company that will cover me.”

One possibility: divorce. This was suggested by Martin’s legislator and insurance advocates in the bleeding disorder community. Divorcing Janeen would leave Martin poor enough to qualify for Medicaid. But to Martin, a devout Christian, this is unthinkable.

A side effect of his ordeal, says Martin, is “the daily stress and worry about health problems, and an overwhelming sense of helplessness. It saps my energies to deal with other things, like helping my son plan for college, enjoying my grandchildren, and participating fully in life.”

In September 2009, Martin con-

tacted Sally McCarty, insurance and advocacy consultant for the Hemophilia of Indiana chapter of NHF. Sally advocated for Martin with the Centers for Medicare and Medicaid Services (CMS) of the US Department of Health and Human Services (HHS), encouraging Missouri’s high-risk pool to consider Martin as a new, federally eligible individual when he reaches the lifetime maximum on Janeen’s plan.

After continuing to work with NHF and Health and Human Services, Martin learned that the Missouri high-risk plan now will accept him when he caps out. Sally showed Martin a December 2009 letter from CMS to all state insurance commissioners in the nation explaining that high-risk insurance pools are the “alternative mechanism” for states to provide access to medical coverage for all federally eligible individuals. Because Martin meets

all eligibility requirements after capping out on the high-risk plan, and is not eligible for Medicare or Medicaid, Missouri must allow him to re-enroll as long as HIPAA guidelines are followed (though a lifetime maximum will still apply).² Sally told Martin, “You have really made a difference!” Advocacy and effort can pay off.

And today? Martin will reapply to the MHIP high-risk pool. Because he expects high premiums, he plans to work with PSI to get help paying them. “And I think my next endeavor may be public speaking on these issues,” he notes. “No one should have to deal with this amount of stress over getting and keeping insurance. Healthcare reform could fix this.”

Though his solution isn’t perfect, Martin says, “I’m extremely thankful that I now have a plan to move to. It’s an answer to many prayers!” —*✧*

2. The 1996 Health Insurance Portability and Accountability Act (HIPAA) protects health insurance coverage for workers and their families when they change or lose their jobs, and prevents those with pre-existing medical conditions from being denied insurance when switching to a new group policy. But remember to always check with your state to learn about specific federal eligibility requirements.

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only to full-time students. These laws do not benefit young adults whose parents are without private coverage themselves.

To begin your research, first contact your parents’ employers’ insurance company to confirm the policies regarding your insurance eligibility. If you are 19 and not a full-time student, you’ll need to research other options. If you have been on your parents’ insurance, but now no longer qualify for coverage, the best option for someone living with a bleeding disorder is to apply for COBRA: this gives you an additional 18 months of insurance coverage. If you’re attending school, check with your parents’ insurance company or human resources

department to find out how long you will remain covered. Many insurance companies offer individual policies, but due to pre-existing illness clauses, it’s nearly impossible for someone with a bleeding disorder to get this kind of coverage. You may also want to ask if you are eligible for your state’s Medicaid or hemophilia assistance programs. Remember, it’s essential not to exceed 63 days without coverage. After that, pre-existing condition restrictions may apply, and you may end up with a long waiting period for coverage.

Many resources exist to help you, including your HTC social worker, your local chapter, your insurance case manag-

er, and your parents’ human resources departments. As a young adult, developing a thorough understanding of your insurance situation will help you become your own advocate and give you the skills to overcome future insurance obstacles. —*✧*

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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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