June 2011

PEN's Insurance Pulse

Inspiring Advocacy

Inside

The High Cost of Healthcare Reform

Will Out-of-Pocket Costs Overtake the Gains?

by Laurie Kelley

Imagine you have a credit card with no limits, and with no payments due from you. Whatever you want, you simply buy. The bill is never sent to you directly. Perhaps the bill is sent to your employer, who deducts a monthly amount from your paycheck. Or the government pays the bill and then raises your taxes to cover costs. But you never actually see how much things cost, and you don't think about what you are buying. How do you think that would influence your spending habits?

Most likely, you'd spend freely and abundantly. You'd look less and less at the cost of what you buy, and you wouldn't bother to compare prices or hunt for bargains. It's true: when we don't have an immediate consequence, we seem to pay less attention to long-term consequences. And yet, you'd eventually notice your taxes creeping up or your paycheck size diminishing.

continued on page 4

Welcome

PEN'S INSURANCE PULSE

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It's been a year since the passage of the landmark national healthcare reform act, officially called the Affordable Care Act (ACA). The initial euphoria for families with bleeding disorders has faded a bit to puzzlement. How does ACA affect treatment options and cost of treatment? Will the act be rescinded because some Congress members and representatives oppose it?

Of course, the positives of healthcare reform are many: regardless of whether they are in college or are married, children can stay on their parents' insurance until age 26. Our children with bleeding disorders won't be denied insurance just because they have an expensive medical condition to treat. Best of all, there are no more lifetime limits on insurance. Over the years, I've heard many heartbreaking stories of families driven into bankruptcy, losing jobs, and becoming dependent on their states to pay for their healthcare, all because of lifetime caps.

But there will be fallout from the passage of healthcare reform. Insurance companies, state budgets, and some politicians are wary of how the new

law is affecting the cost of doing business and impacting our economy. It's a complicated, ever-changing situation.

In this issue, we examine one way that ACA may impact us all: out-of-pocket costs. Regardless of what happens on Capitol Hill or your own state capitol, the benefits and cost savings to you from ACA may unintentionally trigger other costs that could directly affect you. Please read this issue carefully, and bring it to your HTC social worker or your employer's human resource department to discuss.

And if you can attend one of our *Pulse on the Road* programs this year, I look forward to meeting you, discussing healthcare reform, and learning how ACA has affected you.

Laurie

Full Circle

Insurance Lost—Then Regained through ACA

by Kevin Correa

After months of partisan negotiating, the Patient Protection and Affordable Care Act (PPACA) became law in March 2010. It was later called the Affordable Care Act (ACA). You already know about this act, and you're probably familiar with at least some of ACA's provisions.

What often gets lost in the political jockeying is that ACA affects real people. Let's look at the law's enactment in a human context, and learn what the transition into this new healthcare era has meant for one family with hemophilia.

Meet the Mitchells

Amy and Martin Mitchell* have three sons. Brian (20) and Mark (14) have severe factor VIII deficiency with inhibitors. Peter (15) does not have hemophilia.

Maintaining insurance coverage for Brian and Mark has been challenging. In 2003, both boys reached their maximum lifetime benefits under their policies at that time. They subsequently enrolled in their state's high-risk plan. In 2005, Brian and Mark became eligible to join a new policy through their father's employer. Within a year, both boys had again reached their lifetime caps, and were forced back into the state's high-risk pool.

To curb the high cost of the boys' medical insurance, the family applied for several policies. "We were constantly refused by other plans," says Amy. And although Amy's and Martin's weekly work schedules had each been reduced to 32 hours, their income remained just above the limit to qualify for their state's Children's Health Insurance Plan (CHIP).

As it turns out, the state's high-risk pool, designed to help families in precisely the Mitchells' circumstance, proved a major source of stress for the family. Amy recalls, "We had to negotiate a lot of red tape, and endured frequent terminations from the plan."

In one instance, Amy wrote a single check for both boys' premiums, which resulted in the termination of one of the policies. It took four anxious months and two appeals to get the plan reinstated. Most recently, Brian's policy was terminated over a $5 mistake (but was eventually reinstated).

Amy was often overwhelmed by the incessant fear of losing her sons' insurance coverage: "The high-risk state plans are very difficult to deal with, and I had to spend of lot of time appealing decisions."

As debate raged over the proposed healthcare reforms, the Mitchells hoped to find a light at the end of their tunnel.

continued on page 14

*All names have been changed for privacy.

Some provisions of ACA will affect many with bleeding disorders. Because some of these reforms carry exemptions based on the type of insurance plan, please view the following as general guidelines. Researching ACA at www.healthcare.gov will help determine if a given provision affects you.

Children's Pre-Existing Conditions
"The new law includes new rules to prevent insurance companies from denying coverage to children under the age of 19 due to a pre-existing condition."

Eliminating Lifetime Limits
"Under the new law, insurance companies will be prohibited from imposing lifetime dollar limits on essential benefits, like hospital stays."

Pre-Existing Condition Insurance Plan (PCIP)
"A Pre-Existing Condition Insurance Plan will provide new coverage options to individuals who have been uninsured for at least six months because of a pre-existing condition."

Young Adult Coverage until Age 26
"Under the new law, young adults will be allowed to stay on their parent's plan until they turn 26 years old."

Source: *Timeline: What's Changing and When*, www.healthcare.gov

Now, what if the credit card company suddenly required you to pay a fixed amount with every purchase, say $50. How would *that* affect your spending?

This is the idea behind out-of-pocket costs—the portion of your medical bills that you must pay. Maybe it's $20 for a $160 doctor's office visit, or $25 for a prescription for a $300 pain medication. Even people with the best medical insurance coverage must pay out-of-pocket costs. Originally, out-of-pocket costs were designed to make us share part of overall healthcare costs, to help us make better decisions, and to think twice before we rush to the pediatrician, chiropractor, or emergency room and incur hundreds or thousands of dollars in medical expenses.

But out-of-pocket costs are now a concern within the bleeding disorder community, in direct response to healthcare reform. With lifetime maximums gone, and with no pre-existing conditions to deny costly patients—like those with bleeding disorders—from healthcare policies, it's as if we all have credit cards with no limits.

What will this mean for us as healthcare consumers? Insurers will be dishing out more reimbursement money to cover higher and more frequent medical bills, and looking for ways to offset those costs. They can't impose lifetime limits anymore. And they can't keep expensive people, like those with hemophilia, from signing up. So they may hit us where it hurts—in our wallets.

Here's what you need to know about out-of-pocket costs: what they are, how to monitor them, and where to go when you need help paying them.

What Are Out-of-Pocket Costs?

These are the costs you must pay from your own savings and earnings—out of your own pocket. Because each policy differs in what's covered and how much you must pay, your insurance policy will tell you which services include out-of-pocket costs.

There are several types of out-of-pocket costs, and your policy might require one, some, or all:

- *Deductible:* The annual amount of money you must pay first, before your insurance policy's coverage begins. *Example:* You must pay $1,000 before your insurance company will pay for any type of healthcare service.
- *Coinsurance:* The amount (usually a percentage of costs) you must pay before your insurance policy will cover the rest of the cost of a medical service. *Example:* You have a procedure that costs $2,000; your insurance policy requires you to pay a coinsurance amount of 20%, and the insurance company will pay the additional 80%.
- *Copayment:* The dollar amount you must pay for a medical service. *Example:* Your visit to the doctor's office costs $160; your policy requires you to pay $20 per visit, and your insurance company will cover the rest. Copayments can also be required for pharmacy prescriptions.
- *Out-of-pocket maximum:* The annual amount that you must pay directly for healthcare services and drugs under your medical benefit; includes copays, coinsurance, and deductibles. After you reach this maximum, your insurance company will pay 100% of the costs.
- *Annual policy insurance premium:* The actual cost of the insurance policy, usually paid monthly, quarterly, or annually. Normally this cost is shared between an employer and the insured person.

Most Americans, about 65%, have private health insurance though their employers. Employers pay most of the *premium*—the cost of the policy—while employees are responsible for paying out-of-pocket costs as prescribed by their plan. Each plan has different out-of-pocket costs and requirements. Usually, employees must also pay part of the premium cost.

People using Medicaid or Medicare also must pay out-of-pocket costs, and the state will assign a caseworker to explain these costs.

Regardless of how your healthcare costs are covered, your job is to read your insurance policy carefully, understand what out-of-pocket costs are, and try to predict how much your healthcare will cost you directly in a given year. This will help you plan your budget, and help you keep an eye on out-of-pocket costs before they start creeping up.

Healthcare Reform Fallout

Healthcare reform was enacted by the Patient Protection and Affordable Care Act (now just ACA) in March 2010. This landmark act may represent the greatest change to healthcare in American history. Because PPACA eliminates lifetime caps and prohibits discrimination against pre-existing conditions,[1] no insurance company can cut you off because you've used up all your insurance money, or prevent you from being insured because you have a bleeding disorder.

It is our community's hope that because of ACA, more people with hemophilia will be insured and can use as much factor as they need. If this proves true, then costs related to bleeding disorders, already expensive, will undoubtedly increase—with insurance companies now mandated to pay for them.

Ultimately, who will pay for these higher costs?

That's the debate raging now in Congress. ACA makes provisions for some of these costs to be covered

1. The new regulations concerning pre-existing conditions apply only to people under age 19 until 2014, when everyone will be included.

Where is your factor covered?

Any health insurance plan has two parts, representing two different budgets.

- **Medical benefit (major medical):** covers all clinical services including doctor visits, diagnostic tests, surgery, and inpatient drugs
- **Pharmacy benefit:** covers outpatient drugs

through *exchanges* (see "Where to Get Help," p. 7). But advocates worry that insurance companies will raise their premiums even higher to compensate. If premiums rise, employers who must pay these premiums may choose policies that shift more healthcare costs to their own employees. For example, to help lower their premium costs, employers are now pushing for *high-deductible plans* with higher out-of-pocket costs for the patient.

"We were actually headed this way *before* healthcare reform began," notes Michelle Vogel, executive director of the Alliance for BioTherapeutics, Washington DC, and person with von Willebrand disease. "But once it hit, I think insurers jumped in and intensified matters. Shifting more costs to consumers will happen, is happening. It's *all* about shifting costs to consumers now."

Carri Nease is a symptomatic carrier and mother of twins with hemophilia. "Insurance companies have already started hiking out-of-pocket costs," she warns. "My husband's employer switched plans without letting the employees know this past year. Suddenly, in July 2010, we had an unexpected out-of-pocket cost of nearly $5,000 and I had just gotten a deep thigh bleed, which became infected. I was an inpatient for several days—right after we found this out-of-pocket cost. We've been struggling to catch up with our bills since then."

Employers are already seeing premiums increase. Health insurance premiums for employers rose 131% in the last decade, and now average $13,375 per year for family coverage. At the same time, there is a sharp increase in employee contributions to those premiums, up 128% in the last decade to $9,860 per year.[2]

Many of the biggest US companies are complying with ACA.[3] But these companies also plan to shift more costs to their employees to encourage them to limit spending, and to limit rising costs. A recent survey showed that 46% of businesses surveyed expect their costs for healthcare benefits to rise an average of 8.9% in 2011, and they plan to raise the maximum level of out-of-pocket costs that employees must bear.[4]

Private employers aren't the only ones with a cost-shifting burden. "Healthcare reform and subsequent cost shifting will cost states more, through [higher enrollments in] high-risk pools and Medicaid," warns Vogel. And according to Jason Shafrin, an analyst at Acumen, a firm that conducts policy research on Medicaid and Medicare, "Medicaid is pretty volatile now, trying to expand coverage for more people, while states are already in a budget crunch. States are trying to determine who is eligible and then, how to pay for them."

Cost shifting to patients could also create another set of problems, beyond budgetary.

Health Dangers of Higher Out-of-Pocket Costs

Facing higher personal expenses, as costs are shifted to their deductibles and copays, employees and patients may consider cutting back on doctor visits and prescriptions to save money. The general economic decline may also contribute to reduced personal spending on health: higher out-of-pocket costs and lower incomes are a recipe for limited healthcare.

One survey found that 26.5% of Americans have reduced their use of routine medical care since the start of the global economic crisis in 2007.[5] This is a shockingly high percentage compared to patients in other developed countries: 5.3% in Canada, 7.6% in Britain, 10.3% in Germany, and 12% in France. And the greater the out-of-pocket costs in a country, the less money patients spent on healthcare. For example, in Britain and Canada, which have lower out-of-pocket costs than the US, the percentages of patients cutting back on routine care were much lower.

This survey also found that young people, who commonly have lower incomes, were most likely to cut back on their routine medical care. If general trends like this are also true for people with bleeding disorders, then healthcare reform could become a double-edged sword—no more lifetime limits or problems getting insurance, but out-of-pocket costs that still make patients think twice before infusing or visiting the HTC.

David Linney, a private healthcare consultant with a specialty in hemophilia, believes that increased out-of-pocket costs are not so much a response designed to make patients think twice before spending on healthcare. Instead, this is a way to cope with spiraling healthcare inflation, which far exceeds regular inflation. As of August 2010, healthcare inflation was 7.3%, compared to consumer inflation at

2. Sipkoff, Martin. "Higher Copayments and Deductibles Delay Medical Care, A Common Problem for Americans." *Managed Care* Jan. 2010: 46–49. 3. Lentz, Jon. "Health Reform Spurs Change for Big Employers: Survey." *Reuters*. Web. 18 Aug. 2010. http://www.reuters.com/article/2010/08/18/us-employers-idUSTRE67H2LX20100818. 4. Young, Jeffrey. "Paychecks to Shrink Because of Higher Health Premiums, U.S. Companies Say." *Bloomberg*. Web. 18 Aug. 2010. http://www.bloomberg.com/news/2010-08-18/paychecks-to-shrink-because-of-higher-health-premiums-u-s-companies-say.html. 5. Pear, Robert. "Economy Led to Cuts in Use of Health Care." *New York Times*. Web. 16 Aug. 2010.

1.1%. The rising cost of healthcare for employers and state and federal programs "is untenable," says Linney.

As employers take on greater insurance premium costs, they are passing on more costs to employees, especially for expensive drugs.

Many a Tier

About 75% of hemophilia patients have their factor covered through the medical benefit side of their insurance policy, which usually does not categorize drugs into *tiers*. Tiers are classifications of drugs within a formulary that allow insurance companies to assess different out-of-pocket expenses.

There are typically three tiers, and most patients know that if they opt for a generic drug (tier 1) and not a brand-name drug (tiers 2 and 3), they pay the lowest copayment, usually $10 to $50. It's a good system for managing your budget and healthcare costs. For example, the number of US patients abandoning the more expensive brand-name prescriptions at pharmacies has climbed from 5% in 2006 to nearly 10% in 2010.[6]

A fourth tier has been created: the *specialty tier*. Specialty tier 4 can charge coinsurance instead of flat copays on drugs that costs more than $500, and on infusible and injectable therapies. Vogel says, "Coinsurance is currently costing patients hundreds to thousands of dollars in out-of-pocket costs per month, with no cap on what percentage they charge in coinsurance." And she notes, "Most patients don't know anything about tiers." Patients who were used to having factor covered at lower copays can be caught off guard by these higher copays.

Nease is worried. "The next thing I'm expecting is that our factor will become a tier-4 medication. I worry about costs, as a parent of multiple children with severe hemophilia, inhibitors, and one child with asthma."

Fortunately, factor coverage for most patients with hemophilia is covered under the medical benefit of their health insurance and will not be impacted by these formulary changes. Where there is a push toward specialty tiers, some states, like New York, are trying to block their use.

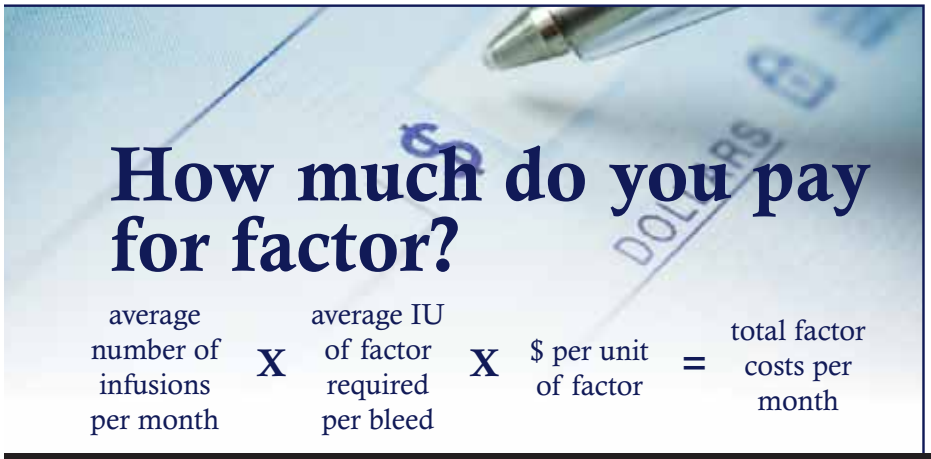
How to Estimate Out-of-Pocket Costs

While we all wait to see how healthcare reform fallout progresses, start protecting yourself and your family by estimating your out-of-pocket costs. Here are three things you must do:

1. *Know your policy requirements.* Are you required to pay $10 or $20 for a doctor's office visit? $25 or $50 for an emergency room visit? Knowing this can help you make good decisions: if you pay only $20 to see your doctor, but pay $50 to visit an ER, you may want to see your doctor if the illness or injury happens during office hours—you'll save money. Your insurance card usually lists the required copay for various kinds of medical visits.

2. *Estimate known costs.* Some costs, such as emergency surgery or hospitalization, are unpredictable. Other costs, such as clinic visits and even specific bleeding patterns, are predictable. If you must pay $2,000 coinsurance before your policy kicks in at 100%, then this is a fixed out-of-pocket cost in a calendar year. Know what you pay per unit of factor and what your typical usage is per week.

3. *Keep accurate records.* It's hard to estimate costs if you don't know what you're paying. Imagine hiring a financial planner to help you create a household budget, yet not knowing what you pay for groceries, gas, or rent because you never look at the bills! An accurate, written record helps you keep track of costs. Maintain comprehensive records of your insurance policy; receipts for out-of-pocket expenses (cancelled checks, cash receipts, credit card statements); your Explanation of Benefits (EOB); and records of infusions, office visits, and medical procedures, including dates. Insurance companies sometimes make billing mistakes, which can affect your bottom line.



Safeguard Your Budget

To make sure you can afford your out-

6. Williams, Misty. "Companies Switching to High-Deductible Health Plans." *The Atlanta Journal-Constitution.* Web. 8 Mar. 2011. http://www.ajc.com/business/companies-switching-to-high-834481.html. The article quotes Paul Fronstin, Director, Health Research & Education Program at the Employee Benefit Research Institute, Washington, DC.

of-pocket costs, you'll need to be your own best advocate to avoid paying more than you have to. The more information you have about prices and procedures, the better armed you'll be to reduce your costs.

• *Know your cost per unit of factor.* It all starts here. This is your highest single cost, and it's easy to get information about this price. When you know what you pay, you may be able to find a lower-priced product or a factor provider who sells your product at a lower price.

• *Examine your EOBs carefully.* Request itemized hospital bills to be sure you're charged only for what you used or ordered. Watch for mistakes in services, amount of factor ordered, and duplicate charges.

• *Question healthcare services.* Make sure that all services are medically necessary. Ask in advance why a procedure or device is being ordered and how much it will cost. Eliminate unnecessary items or services. Fancy packaging or home nursing services, for example, can add extra cost. A simple cloth sling from the orthopedics department could add $30 to your out-of-pocket costs—but most likely, no one will tell you that at the time your doctor recommends it.

• *Explore home- or self-infusion.* Visiting the ER for an infusion is expensive. If your insurance covers it, have a nurse come to your home to infuse; or when you feel ready, learn how to infuse your child.

• *Get an MSA (pre-tax medical savings account).* Estimate costs, and put money toward the MSA, which also covers new eyeglasses, ancillaries, and over-the-counter medications.

• *Consider secondary insurance.* Obtain a policy through your employer or on your own.

• *Coordinate multiple insurance policy benefits.* If your spouse has an insurance plan, you might be able to submit your out-of-pocket costs to that plan for reimbursement.

• *Compare the prescribed dose with the dose delivered.* "Dose creep" happens when your factor provider delivers more IU per vial than you need, costing you extra money. If your child needs 1,300 IU and your factor provider is giving you 1,500 IU, that extra 200 can really add up if you are paying out of pocket for prescriptions. Make sure your factor provider has a good range of IU sizes of your factor brand so that what you receive matches as closely as possible the amount your doctor prescribed.

Where to Get Help

Even when you know your policy, and you've taken precautions to cut costs and monitor expenses, you may still have trouble paying out-of-pocket expenses. Here's where to go for help:

• *Your HTC social worker*. This professional should always be your first stop for insurance help.

• *Reimbursement programs.* Many home care and pharmaceutical companies offer help if you can prove financial hardship. They may waive fees or portions of the bill, or even provide free product. Visit your factor manufacturer's website and look for the reimbursement help section.

• *Bleeding Disorder Legal Information Hotline.* Call toll-free with any insurance questions: 800-520-6154.

• *Patient Services, Inc.* PSI may be able to help you meet the out-of-pocket costs you can no longer pay.

• *Baxter's CARE Program:* This comprehensive insurance assistance program is open to all hemophilia A patients and inhibitor patients, regardless of current therapy or insurance coverage. Contact your Baxter representative or call toll-free: 888-BAXTER9 (888-229-8379).

• And more help is coming: you may be eligible for a credit for your premiums. In January 2014, ACA will allow premium credits to be issued to assist families with out-of-pocket expenses, through state-established *American Health Benefit Exchanges*. Your HTC social worker can help you determine whether you qualify for this credit.

Get Involved

Bleeding disorder families must advocate for their own health insurance needs, and also explain these needs to healthcare professionals, employers, and legislators who can help. Nease would have been financially burdened if the teacher's union hadn't advocated for her. "My husband is a county school employee," she says, "and school system insurance is on a fiscal calendar. Our insurance is on a calendar year, and was set to renew the out-of-pocket costs in January, which would have given

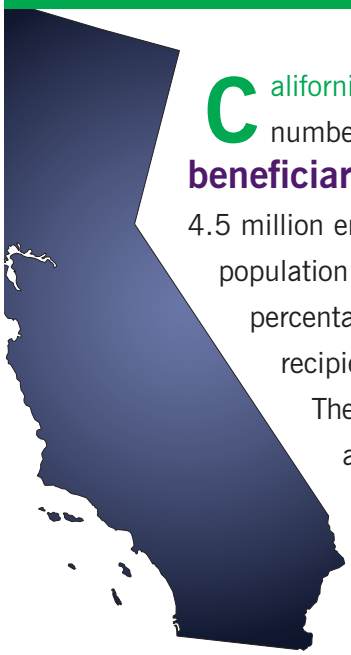
continued on page 15

Pulse *on the Road* upcoming programs

Great Lakes Hemophilia Foundation Annual Meeting	The Lone Star Chapter of the NHF Texas Bleeding Disorder Conference	Oklahoma Hemophilia Foundation Annual Meeting	Hemophilia of North Carolina Family Retreat
Wisconsin Dells, WI	San Antonio, TX	Tulsa, OK	Pine Knoll Shores, NC
June 11, 2011	June 26, 2011	July 30, 2011	August 27, 2011

www.kelleycom.com/potr_event_dates.html

Tracks & Trends



California has the largest number of **Medicare beneficiaries** of any state: 4.5 million enrollees. As the population ages, the state's percentage of Medicare recipients will increase. The number of Californians aged 65 and older will **more than double** between 2000 and 2030.

More than **400 new drugs** now in the pharmaceutical product **pipeline** are predicted to cost more than **$50,000** per course of treatment.

Drug Benefit News
Aug 2010, Vol 11, No 16

Who will pay for healthcare?

The chart shows ten states with the largest projected budget deficits for FY 2012. Deficit states will have a serious problem paying for healthcare.

Danielle Kurtzleben, *U.S. News & World Report*, Jan 14, 2011

Family health insurance premiums **rose 3%** to $13,770 in 2010, while employees' out-of-pocket healthcare expenses **jumped 14%** as firms shifted the cost burden.

Kaiser Family Foundation
www.kff.org/insurance/090210nr.cfm
Sept 2, 2010

State	Projected FY 2012 shortfall (billions)
California	21
Illinois	17
New Jersey	10.5
Texas	10
New York	8.2
Connecticut	3.8
Minnesota	3.8
North Carolina	3
Ohio	3
Florida (tie)	2.5
Oregon (tie)	2.5

Only 25% of Americans scored 7 or more of 10 questions **correct** in a recent quiz on healthcare reform.

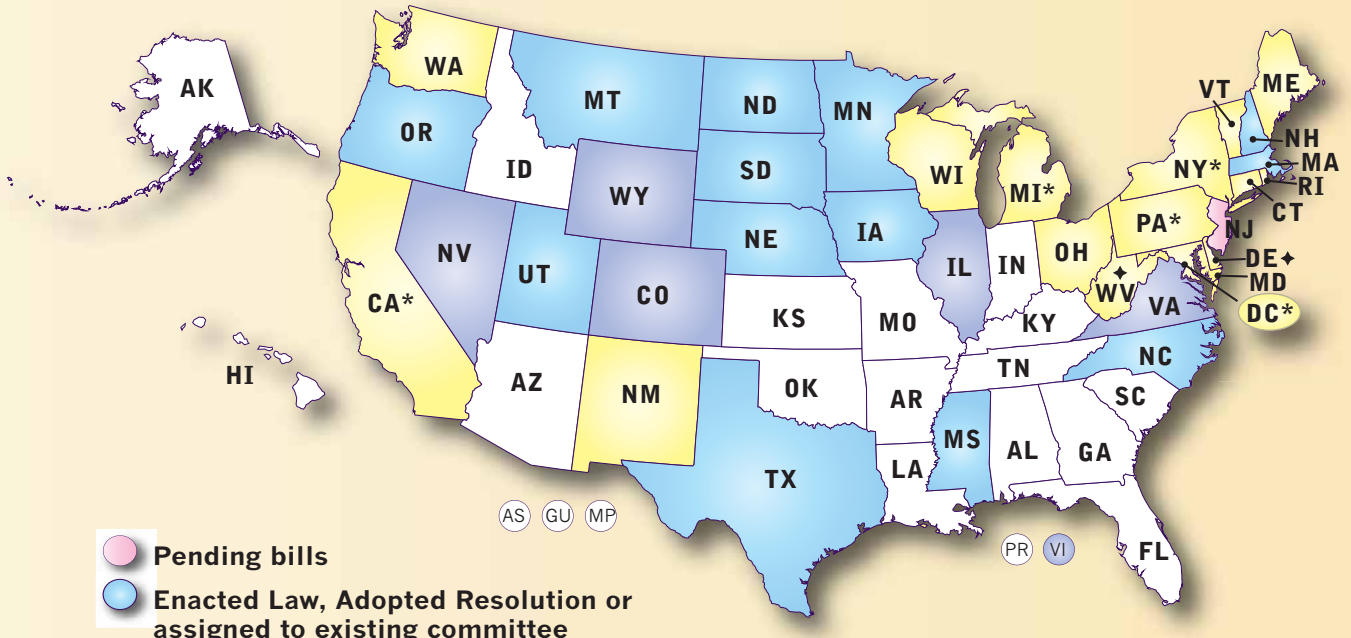
Kaiser Public Opinion, Feb 2011

About **$700 billion** (5% of US GDP) is wasted on **unnecessary medical care**, including extra costs related to medical errors, defensive medicine, and fraud, as well as "unnecessary" ER visits for minor conditions—colds, headaches, feverish babies—that could be handled more cheaply in doctors' offices.

Peter Orszag,
director of the federal Office of Management and Budget,
cited in "Are Most Emergency Room Visits Really Unnecessary?"
Zachary F. Meisel and Jesse M. Pines
Mar 9, 2010
www.slate.com

The US spent
$2.5 trillion
on healthcare in 2009.

2010 State Actions Implementing Health Reform



- Pending bills
- Enacted Law, Adopted Resolution or assigned to existing committee
- Executive Action
- Legislative and Executive Action

* Introduced bills currently pending in the legislatures

✦ Legislative action/enacted law requires executive action by the state or governor

Federal Health Reform State Implementation, National Conference of State Legislatures, Jan 11, 2011

Ask the Expert

by Mike Bradley
Vice President of Healthcare Economics and Reimbursement, Baxter BioScience

Q: What is the Medicare donut hole?

Most Medicare Part D prescription drug plans have a gap in coverage called the *donut hole*. This means that after you and your drug plan have spent a certain amount of money for covered medications, you must pay all costs out of pocket for your prescriptions up to a yearly limit. What counts toward this out-of-pocket limit? Your yearly deductible, your coinsurance or copayments, and the donut hole amount. The limit doesn't include the drug plan premium you pay or what you pay for prescriptions that aren't covered.

Some plans offer coverage during the gap; for example, for generic drugs. But plans with gap coverage may charge a higher monthly premium. Check with the drug plan first to see if your prescriptions will be covered during the gap. For more information, visit www.healthcare.gov. Or call 800-MEDICARE (800-633-4227) to see if a copy can be mailed to you.

The 2010 healthcare reform act, also known as Patient Protection and Affordable Care Act (PPACA), has made some significant changes for those affected by the donut hole. If you reach the coverage gap in 2011, you'll get a 50% discount on covered brand-name prescription drugs. You'll have additional savings in the coverage gap each year through 2020, when the law mandates that you will have full coverage in the gap—meaning the donut hole goes away. Talk to your doctor or healthcare provider to make sure that you're prescribed the lowest-cost drug available that works for you.

Please remember that your factor is covered under the Part B drug plan, *not* Part D. Factor will not be impacted by any changes to Part D.

Here are some specifics on how the Part D prescription drug plan will work now and into 2014:

- If you join a Medicare prescription drug plan in 2011, you may have to first pay up to $310 of your drug costs. This is the *deductible*.
- During the initial coverage phase, you pay a copayment or coinsurance, and your Part D drug plan pays its share for each covered drug until your combined amount (including your deductible) reaches $2,840.
- Once you and your Part D drug plan have spent $2,840 for covered drugs, you will be in the donut hole. Previously, you had to pay the full cost of your prescription drugs while in the donut hole. But in 2011, you get a 50% discount on covered brand-name prescription medications. The donut hole continues until your total out-of-pocket cost reaches $4,550. This annual out-of-pocket spending amount includes your yearly deductible, copayment, and coinsurance amounts.
- When you spend more than $4,550 out of pocket, the coverage gap ends, and your Medicaid Part D prescription drug plan pays 95% of the costs of your covered drugs for the rest of the year. You will then be responsible for a small copayment.

Q: In healthcare reform, what does it mean if my insurance plan is *grandfathered*?

The PPACA contains provisions that allow some existing insurance plans—those that don't significantly raise prices or reduce benefits—to maintain a grandfather status. These plans are not affected by all changes implemented by healthcare reform. The goal of creating grandfather status was to help smooth the transition to major insurance changes mandated by law in 2014.

A grandfathered health plan is a private insurance plan that (1) provides coverage on a fully insured (usually through an employer) or self-insured basis, and that (2) existed on March 23, 2010—the date PPACA was enacted (the *grandfather date*).

Grandfathered health plan coverage includes coverage of an individual and the individual's family members enrolled in the group health plan on the grandfather date. As long as someone on the plan stays covered, the plan will maintain its grandfather status.

Grandfathered health plans may permit newly hired or newly enrolled employees and their families to enroll in the plan after the grandfather date without jeopardizing the plan's grandfather status. For example, an employee can switch from one grandfathered health plan offered by the employer to

continued on page 15

A Military Plan:

Advocate, Persist, Prevail

by Sara P. Evangelos

When Heather Messerly's fifth child, Trevor, was born with severe hemophilia A, Heather soon learned that she needed more than just a working knowledge of hemophilia. She needed to understand her insurance plan, to be prepared for changes, and to question everything.

Because Heather had no family history of hemophilia, "the initial diagnosis was so overwhelming, I really wasn't thinking about insurance; the most important thing was to learn about hemophilia." But, she adds, "I've gotten more into the insurance side in the past few years."

True, there's only so much you can fit in your head after the diagnosis. But you need to consider insurance. Facing insurance challenges, especially in today's healthcare climate, requires perseverance and advocacy. Like Heather, you must be proactive about your family's healthcare.

In the Navy—For Now

Heather lives in California with her husband Jeff and their five children: daughters Alexis, 15, Madison, 13, and Jordan, 11; and sons Brandon, 17, and Trevor, 8.

Jeff is a career US Navy officer. This summer, having served his 20 years, he'll retire. Right now, he's interviewing for new jobs. Fortunately, after Jeff retires, the family will be able to keep its Tricare military insurance, which has never had lifetime caps. The policy will be slightly more expensive, but manageable. Still, says Heather matter-of-factly, "With five kids, we always have to consider expenses."

Even with one insurance plan guaranteed, Jeff's career decisions are influenced by the kind of insurance available from prospective employers to supplement the family's Tricare coverage. One potential employer offered an insurance plan that Heather knew would be inadequate for hemophilia care. "So that job was not even an option."

Why is the Messerly family choosing employers and coverage so carefully, even when they know they'll have a policy through the military? Because they've already been through one frustrating insurance challenge when they were asked to pay out of pocket for factor.

Generic Factor?

In fall 2009, Tricare informed Heather that her family could no longer use its current home health care company, and advised her to fill Trevor's prescriptions at Kmart. "I got a letter listing two pharmacies I could use that were 'close to my current company'—Long's Drug Store and Kmart," recalls Heather, laughing. "They had *no idea* about factor and hemophilia."

So Heather called her insurance company immediately. Where would she obtain Trevor's factor while she was settling her insurance problems? "I was told that if I could not use Kmart, I should just pay out of pocket until things were worked out. When I explained the cost of factor, and that I couldn't possibly afford this, I was lectured on the fact that I was not using a 'generic version.'"

The next day, Heather began documenting everything. She contacted

Trevor Messerly, age 8

the head hematology nurse at Rady Children's Hospital, San Diego, who called the director of Federal Hemophilia Treatment Centers Region IX. Heather also called her home care company, and learned that the company was unaware that it was being dropped from Tricare.

Persistence and Advocacy Required

"Then began my month-long quest," Heather reports. "I would call my pharmacy, and they would say, 'No, that's a medical benefit.'" So I would call the medical side, and they would say, 'No, that's a pharmacy benefit.'" Heather's insurance company did provide a list of other home health care companies. But when she contacted these companies, she learned that they were also being dropped. She was amazed. "Even Tricare was suggesting companies that they were dropping!"

Heather then appealed to a friend who worked for a different home care company. When her friend began investigating, he learned that his own company, too, had been dropped by Tricare.

Finally, five weeks after Heather's experience began, a staffer at Hemophilia Association of San Diego County (HASDC) phoned US Congress member Duncan Hunter of California's 52nd district, on Heather's behalf. "Within thirty

continued on page 15

Community Forum

How has the new healthcare reform impacted state Medicaid programs?

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

Art Wood

Senior Vice President, Marketing and Development, Patient Services, Incorporated

Medicaid and Children's Health Insurance Program (CHIP) insure about one-third of children and over half (59%) of low-income children, providing access to needed care.[1] Medicaid also covers about 15 million adults who generally have no access to job-based coverage; acute and long-term care for 8 million non-elderly people with disabilities; and nearly 9 million low-income elderly people with disabilities who need long-term care. Overall, Medicaid covers almost 30 million low-income Americans and uses 16% of national health spending, including 40% of spending on long-term care services.[2]

Healthcare coverage expansion is the centerpiece of President Obama's Affordable Care Act (ACA). To help reduce state-by-state variation, this new law expands Medicaid to 133% of the federal poverty level (FPL)[3] beginning in 2014 ($16,678 for an individual, or about $34,194 for a family of four in 2011). This would also include non-Medicare eligible adults under age 65 without dependent children. Eligibility would be determined without an in-depth review of assets. Those with incomes between 133% and 400% of FPL would receive subsidies through state-based exchanges to be developed over the coming years.

What is the impact of ACA on Medicaid moving forward? First, states will receive federal matching funds (at varying rates in the years ahead) to cover those newly eligible people and prevent placing undue strain on state budgets. But a political move is underway to de-fund aspects of ACA, which will affect Medicaid if approved. Second, ACA increases healthcare provider rates to 100% of the Medicare payment. (Currently, many physicians refuse to take on Medicaid patients due to the low reimbursement rate.) Third, ACA provides new funding to states willing to expand Medicaid to cover preventive care beginning January 1, 2013. There is an assumption that better preventive care reduces costs of treatment for acute conditions. Fourth, there will be increases in the manufacturer Medicaid drug rebate percentages for brand-name drugs from 15.1% to 23.1% (except for clotting factor and drugs for pediatric indications, which increase to 17.1%). This will negatively impact manufacturers, but will benefit Medicaid in reimbursing some of the costs.

The challenges in providing increased healthcare are great. Rising costs in state Medicaid programs have forced states to move from fee-for-service reimbursement models to managed care models. This may reduce costs but provide obstacles to accessing certain treatments that patients consider necessary. Some states are reining in costs through cost shifting to patients of already limited income. At the same time, some states, including Connecticut, Washington DC, and Minnesota, are taking the initiative to expand coverage even before ACA requires it in 2014. For the chronically ill, the time is ripe to monitor upcoming developments, become educated on changes taking place in your community, and advocate for anything that helps provide access to needed treatment. Feel free to meet with your state Medicaid director and state legislative health committees to discuss the importance of Medicaid coverage to the chronically ill.

Michelle Rice

Regional Director for Chapter Services, National Hemophilia Foundation

First, it's important to note that most states (if not all) are facing budget cuts and have large deficits due to the recession. In the 2010–2011 fiscal year, state budgets had federal

1. See Kaiser Commission on Medicaid and the Uninsured report, "Health Coverage of Children: The Role of Medicaid and CHIP," Feb. 2011. 2. See Kaiser Commission on Medicaid and the Uninsured report, "Medicaid and Access to Care," Mar. 2009. 3. The US Federal Poverty Guidelines are often referred to as the federal poverty level, or FPL.

stimulus funds to help close some of that budget gap. But in 2011–2012, those funds are no longer available. This means that states' share of Medicaid costs is expected to increase 25% or more.

Add to this the fact that healthcare reform calls for state Medicaid programs to expand coverage to single adults and increase financial eligibility from 100% of the poverty level to 133% of FPL, and it's no surprise that states will look for ways to deal with their impending increase in costs.

Medicaid and education are typically the top two largest budget items for states. To address the current deficit, many states will look at cuts in one of these two programs.

Already, some states are responding by doing one or more of the following:

- Cutting provider reimbursement: 39 states have already made cuts.
- Implementing various cost-containment strategies: for example, creating sole-source provider contracts; limiting utilization of services; implementing preferred drug lists; increasing patient cost sharing through increased copays.
- Increasing the use of managed care.
- Eliminating optional benefits: for example, dental benefits for adults; prescription drug coverage for adults.
- Implementing a more stringent Medicaid application process.

To ensure that the needs of people with bleeding disorders are not interrupted or lost, it is critical that as advocates, we continue to monitor the state Medicaid programs and any changes they seek to implement. Further, mobilizing our grassroots activities on the state level will be crucial in ensuring that people affected by bleeding disorders can get the specialized care and services they need.

Valery E. Gallagher
Director, US State Government Affairs, Baxter Healthcare

States are the foundation of the successful implementation of federal healthcare reform. But the Patient Protection and Affordable Care Act (PPACA) and the subsequent Health Care and Education Reconciliation Act of 2010 (collectively called the Affordable Care Act [ACA] or federal health reform) impose monumental requirements on states.

By January 1, 2014, each state must (1) expand its Medicaid program; (2) align state health insurance laws to the new federal health reform requirements, including what essential health benefits all insurers must provide; (3) integrate current state-funded assistance programs; and (4) create an insurance *exchange*. An exchange is a state-directed web-based portal (website), through which states will be required to provide an electronic system that seamlessly matches citizens who do not have health insurance to an appropriate healthcare insurance provider—either a public program like Medicaid or a private one like Blue Cross Blue Shield.

ACA expands Medicaid to cover all citizens and qualifying immigrants who earn up to 133% of FPL, presently $14,404 for an individual and $22,050 for a family of four. The National Conference of Legislatures projects this new mandate will increase today's Medicaid population by over 50%, with some states seeing an increase of over 100%. For example, Indiana projects that its Medicaid population will increase by 44% and that this will cost $2.6 billion annually.

But states are required to enact balanced budgets. This recession has forced states to oversee more than $400 billion in state-funded program cuts over the past three years. The new federal mandate requires states to serve the new Medicaid population while balancing the needs of other state programs. To assist states in managing the higher Medicaid population, the federal government has agreed to reimburse states the increased population's cost of Medicaid services at 100% for two years starting January 1, 2014, and continuing through 2016; and to diminish its support to 90%, with states covering 10% in 2020.

States may require hemophilia patients using state assistance programs, such as Illinois' Hemophilia Assistance Program and California's Genetically Handicapped Persons Program, to get insurance under their expanded Medicaid program—by private insurance through the exchange, with subsidies to assist people between 133% and 400% of FPL; or by agreeing to continue the program fully funded by the state.

States are preparing for the increased Medicaid population in 2014 by advancing Medicaid reforms today: enacting or enhancing Medicaid Managed Care and/or cutting Medicaid provider rates, and cutting and/or eliminating other state-funded health programs, which could negatively impact hemophilia care.

Already, 27 states have filed a lawsuit challenging the new law, and numerous Republican governors were elected to challenge ACA. As a community, we need to monitor state activities to protect our health insurance priorities, whether public, through Medicaid, or private, through health insurance providers. We also need to

continued on page 14

Transitions *from page 3*

End to Lifetime Caps

Prior to ACA, insurance companies could cap a policy holder's lifetime benefits—as they had with Brian and Mark. Now, under ACA, most plans are prohibited from creating such caps.

As a direct result of ACA, in 2010 Brian and Mark were again eligible for inclusion on the Mitchells' policy.

Amy admits that she was caught off guard by their insurance company's proactive response to the new law. "I was very surprised when the insurance company contacted me to see if there was anything they could do to help [with the transition] and to update the boys' records."

For the Mitchells, the transition into the new healthcare system has worked as it was designed. The law helps the family on many levels. For starters, taking the boys off their state's expensive high-risk plan has saved the family $300 a month. Though they are happy with these savings, the Mitchells place even greater value on the peace of mind the law offers.

"The constant worry of [losing the boys' insurance] was too much for us on top of taking care of two children with hemophilia," admits Amy. "The stress actually compromised my health and ability to care for the boys."

ACA has alleviated some of that stress, but with the ongoing political and legal wrangling, the specter of repeal still causes anxiety. "We're worried that everything will be overturned, and we'll be back where we were," Amy concedes.

What's In It for Me?

Large-scale changes in the healthcare landscape can't go smoothly for everyone. It's unlikely that all insurance companies will be as helpful and accommodating as the Mitchells'. For that reason, you should take the proactive step of educating yourself on your rights under the provisions of ACA.

As you begin your research, remember that the reforms will be rolled out over several years, with the majority in place by 2014.

One of the best places to gather information about the law is www.healthcare.gov. This website, administered by the federal government, is easy to navigate and provides a wealth of information on the ACA reforms. You can even enter your state of residence to receive state-specific information. You'll also find information about the exemption of some plans from certain provisions of the law.

There's little doubt that some aspects of ACA will change in the months and years to come. But let's hope that the politicians on Capitol Hill don't lose sight of the fact that these reforms have made a huge difference in the health and well-being of scores of real people with hemophilia like the Mitchells.

Community Forum *from page 13*

monitor gubernatorial actions and the lawsuits, which could reach the US Supreme Court by the 2012 election.

Beth Sufian
JD, Director, Bleeding Disorder Legal Information Hotline; Partner, Sufian & Passamano, LLP

The Affordable Care Act (ACA) will dramatically increase the number of people who are eligible for Medicaid in 2014. In 2014, adults whose household income is below 133% of the Federal Poverty Guidelines will be eligible for Medicaid coverage. But until 2014, most states require adults to be receiving Supplemental Security Income (SSI) benefits in order to be eligible for Medicaid benefits. If a child receives Medicaid benefits before age 18, the child will lose Medicaid coverage after turning 18 unless he or she becomes eligible for SSI at that time.

As of April 1, 2010, states are able to receive federal matching funds to cover some additional low-income individuals and families under Medicaid for whom federal funds were not previously available. This section of ACA is an attempt to make it easier for states to cover more of their residents under Medicaid. If you are living in a low-income household, you may want to check with your local Medicaid office to see if your state has expanded eligibility for Medicaid benefits.

ACA also instituted the new Community First Choice Option, which allows states to offer home- and community-based services to disabled individuals through Medicaid, rather than offering only institutional care in nursing homes.

If you have questions about social security benefits, Medicaid, or other insurance issues, contact the Bleeding Disorder Legal Information Hotline (800-520-6154), created and operated by the Lone Star chapter of NHF through exclusive support from Baxter. The hotline provides free, confidential information on government benefits, insurance, education, and employment.

minutes," says Heather, "Hunter's assistant called me to find out what was going on." Then the congressman's office called Express Scripts, Heather's pharmacy under Tricare. "By that evening, Express Scripts called me, had a list of [companies] I could use, and sent a letter stating how sorry they were." But, Heather wonders, "I don't know why, for the whole previous month, they couldn't tell me *anything*."

Heather's advocacy and persistence paid off. But, she stresses, "It's frustrating to me that it took somebody high up in government to get answers. I had been on the phone with [my insurance company] nearly every other day for a month—and no one was sorry *then*."

Still, Heather considers her family lucky. "Through all this mess," she says, "I never had to pay any extra for factor. My home care company was very good at taking care of us until we could find a new company."

Proactive Today, Protected Tomorrow

Heather still has concerns with her insurance coverage. Currently, she explains, "My copay is based on every single NDC code that comes in my delivery. So it's different every month, depending on how many different codes I have. I can't get a clear answer, and I can't tell if the problem is on the side of my home health care company or on the side of my insurance."

Another concern is simply finding information about her military insurance. "There isn't much printed up on the military side," Heather notes. "It's a whole separate factor arena." Indeed, she has attended meetings on hemophilia insurance coverage, only to hear the disclaimer, "Remember, this does not apply to military insurance."

Despite these frustrations, Heather notes that overall, her family is fortunate with the Tricare plan, which is similar to an HMO. "We don't have as much choice, but we pay less out of pocket." Yet she remains vigilant after her experience.

How can you become an informed, proactive advocate to help protect your family from insurance nightmares? Heather advises making personal connections in the bleeding disorder community, and attending educational events at the local hemophilia association. "Once Trevor was diagnosed, my biggest help was the association. That's where I got the best information." Today, Heather serves on the board of HASDC. "It's my way of thanking them for everything they did for me."

Everybody's insurance coverage and challenges differ. Advocate for your family's needs, and don't give up. Be an insurance watchdog. Whenever possible, reciprocate the help you receive along the way. And learn as much as you can about your specific needs and specific policy!

Healthcare Reform *from page 7*

us yet another out-of-pocket to meet in six months." Nease would have had to pay $9,600 out of pocket. After they successfully advocated, the Nease family now pays $4,800 out of pocket.

Even though healthcare reform has been enacted, it's still passionately debated on Capitol Hill and in each state. No one is sure of the outcome. Will it be repealed? Modified? Time will tell. But don't wait to see what *will* happen. Act *now* to safeguard your healthcare—and your wallet. Vogel recommends that patients become involved in their local bleeding disorder communities and chapters, particularly at the state level, and in advocacy agencies like the Alliance for BioTherapeutics. "We need to avoid the black hole of out-of-pocket costs, especially coinsurance, and make [these costs] a flat rate. Get involved in state legislatures, and tell your story! Make your voice heard—today."

Ask the Expert *from page 10*

another grandfathered health plan offered by the employer without causing either plan to lose grandfather status.

These rules apply to *all* private insurance plans regardless of whether they are grandfathered:

- No lifetime dollar limits on coverage.
- Waiting period for new employee coverage no more than 90 days.
- Coverage of dependent children extended to age 26.

These rules apply to *new* plans, but not to grandfathered plans:

- Limit on overall cost sharing for "essential health benefits."
- Allowable deductible for small-group plans capped at $2,000 for single and $4,000 for family in 2014.
- Coverage of recommended preventive services without cost sharing.
- Consideration of health status in setting premium rates prohibited.

How will you know if your current health plan is grandfathered? Call your health plan or ask someone in your employer's benefits department. Create a list of questions before you ask about any issue. It's essential to understand all aspects of your insurance.

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Inside: High Cost of Healthcare Reform

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PEN's Insurance Pulse

Inspiring Advocacy