PEN's Insurance Pulse

Inspiring Advocacy

Inside

Take the Healthcare Insurance Quiz!

Wendy Owens and Laurie Kelley

Ten points if you know who said this:

There are known knowns; there are things we know that we know. There are known unknowns; that is to say, there are things that we now know we don't know. But there are also unknown unknowns—there are things we do not know we don't know.[1]

Though the quotation is a bit convoluted, the thoughts behind it apply to hemophilia parents and patients trying to understand health insurance reform. What are your "known unknowns" about the rapidly changing world of health insurance?

It's time to test how much you know about the Affordable Care Act (ACA). Changes will happen in 2014 under ACA that will directly impact people with hemophilia. Some changes you really need to know about, so give our test a try. There are no wrong answers when you learn something you didn't know—or didn't know you didn't know!

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Welcome

PEN'S INSURANCE PULSE

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These days, when I get together with my siblings, high school friends, or college mates, we often talk about "launching" our children. And we discuss whose kids are graduating, holding jobs, or interning somewhere. For parents of children with hemophilia, launching may sound like sending them into deep space, where there is no insurance space station. My son is about to turn 26, and he will be expected to have his own source of insurance. Like many his age, he may not understand the terminology, new laws, or healthcare plan options.

This issue is written to test your knowledge about insurance and the Affordable Care Act (ACA), and to educate your young adult child with hemophilia. It will demonstrate areas where you need to gather more information. So much has changed in just a few years, and things will keep on changing. Your child will change, too, as he gets older and eventually reaches the age when he must fend for himself. Read my article in Transitions about how to help him prepare. And for readers who want to look beyond their own situation and help our community maintain access to care, read Kate Muir's article in Real Life about advocacy. Remember, 2014 is a watershed year in insurance. Why? You'll have to take the test to know that!

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

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Turning 26?

When the Real Insurance Action Starts

Laurie Kelley

Hemophilia can provide some scary moments for parents raising their child with the "royal disease." The diagnosis. First bruises. First muscle or joint bleed. First ER visit. First infusion. First missed veins. Self-infusion. Then the regular milestones: First tooth. First sleepover. Kindergarten. Little League. Camp. Driver's license. Going away to college. Drinking. Tattoos.

Hey, I know. Been through it all, and I wrote the book.

But the scariest milestone by far is coming up. My son turns 26 in September.

Pain and Gain

More adults aged 18–25 in the US are uninsured than any other group, lacking even basic health insurance coverage.[1] Some young adults may feel invincible and avoid having health insurance. But rising premiums and out-of-pocket costs may also make insurance too expensive for young adults on their own. Sure, our kids can always go to a federally funded ER for treatment—and young Americans visit the ER more than any other group except seniors. But this is dangerous when you have hemophilia and need routine, weekly care.

Fortunately, the Affordable Care Act (ACA) is making healthcare affordable and accessible for young adults. Three million previously uninsured young adults have joined or rejoined their parents' health insurance plan since ACA allowed children up to age 26 back on their parents' plans in September 2010.[2] In 2014, millions more will be able to afford coverage through the Health Insurance Marketplace, expanded Medicaid, and tax credits.

ACA makes life easier, especially for young adults with chronic disorders including hemophilia. In 2014, there will be no more lifetime maximums on the amount of health coverage an individual can receive. No more annual caps. No more being denied a policy if you have a pre-existing condition such as hemophilia. As long as you pay your premiums and are honest on your application, you can get healthcare coverage.

But there's still a worry: by age 26, young people will be off their parents' plans and back on their own insurance. Think of the consequences for those with hemophilia! What are our young adults with hemophilia doing now to prepare for that day? What are we doing as parents to help prepare them?

Peeples: What You Need to Know

I mean you, almost-26-year-olds: listen up!

First, know that when you turn 26, you will no longer be eligible for your parents' insurance. You will be insurance-less. Not able to order your factor or go to your HTC. Unless you can sell your brilliant Internet start-up to Yahoo quickly, *you need to find insurance.*

Second, start reading about insurance. Know your terminology: What are copays? Coinsurance? Premiums? Formularies? In-network? Out-of-network? Tiers? You have some major homework to do!

Third, know that there is an annual fine for failing to have health insurance: starting in 2014, it's $95, depending on income. Okay, most parents would help pay that for their sons, but avoiding insurance and paying fines is not the answer. The fines get bigger in 2015 and even bigger the next year.

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Healthcare Insurance Quiz *from cover*

Circle your answers, and then check the answer key on page 11 for more information. Download extra copies of the quiz from our website (www.kelleycom.com) and test your family members. Distribute the quiz to audiences at your local chapter events. Good luck!

Liberty, Justice, and Health Insurance for All

1 Which of the following is not a major change taking place in health insurance in 2014?

A. A health insurance tax credit is established for middle-class Americans
B. Insurers are prohibited from dropping or limiting coverage for people participating in clinical trials
C. Patients receive a free box lunch at each doctor's office visit
D. Annual limits on insurance coverage for adults are eliminated
E. No discrimination is allowed based on pre-existing conditions or gender

2 Under the individual mandate, ACA requires all US citizens to have some kind of healthcare coverage beginning in 2014.

True or False?

3 What kind of insurance do I need to meet the individual mandate requirement?

A. Government-sponsored plan
B. Employer-sponsored plan
C. Health Insurance Marketplace plan
D. State health benefits risk pool
E. Any of the above

4 What happens if I don't sign up for insurance in 2014 and each year after?

A. You will be arrested
B. You will pay an annual penalty for yourself and for each of your dependents who remain uninsured
C. Your driver's license will be revoked
D. You will be put on probation by the courts
E. You will have to dress in bubble wrap so you don't get hurt

Healthcare Insurance Marketplace

5 Which of these describes the Health Insurance Marketplace (the Marketplace)?

A. Intended to make buying health insurance easier and more affordable
B. Will offer plans to individuals and small businesses
C. Will offer only Qualified Health Plans (QHP)
D. Will give some consumers financial assistance to pay premiums
E. All of the above

6 Who can enroll in Marketplace plans beginning in Oct. 2013?

A. Only business people selling products and services through their companies
B. Canadian and Mexican citizens under the NAFTA treaty
C. US citizens with annual incomes above $25,000
D. All of the above
E. None of the above

7 Which of these categories will the Marketplace use to define different plans?

A. Precious metals plans: Bronze, Silver, Gold, Platinum
B. Rainbow plans: Red, Orange, Yellow, Green
C. Number plans: 1, 2, 3, 4
D. Smiley plans: 😐,☺,☹,😮
E. Letter plans: A, B, C, D

8 The US federal government will run the Marketplace.

True or False?

Consumer Reforms within ACA: What Will Change for Me?

9 What has already changed because of ACA?

A. Children can stay on parents' health insurance until age 26
B. Insurance companies are prohibited from canceling coverage
C. Unreasonable hikes in premium rates are prevented
D. All of the above
E. None of the above

10 Annual caps will go away in 2014.

True or False?

11 Everyone must purchase a health plan from the Marketplace.

True or False?

12 If I change insurance policies in 2014 or later, the following are reasons an insurer can deny me or my dependents health insurance coverage.

A. I have a bleeding disorder
B. I am female and pregnant
C. I drive a red car (a fast red car)
D. I own a Rottweiler
E. None of the above

13 My insurance company can spend my health insurance premium dollars (what I contribute to my plan) any way it chooses.

True or False?

Medicaid Expansion

14 What is Medicaid expansion?

A. Ballooning cost of Medicaid services
B. Addition of 10,000 new government workers to support Medicaid services
C. New construction for Medicaid offices
D. Expansion of Medicaid to include ages 19 to 65
E. None of the above

15 All states are required to expand their Medicaid programs in 2014.

True or False?

16 How will states pay for Medicaid expansion if 11 million new people are expected to qualify for Medicaid benefits?

A. States will raise state taxes to pay for the expansion
B. States will lay off state workers and reduce class time for public schools
C. The federal government will provide financial support
D. Donut and cookie fund-raisers will contribute

17 If my state chooses not to expand Medicaid, there will be no changes in my Medicaid coverage.

True or False?

Getting Your Money's Worth

18 What are "essential health benefits"?

A. Products similar to essential oils
B. 10 categories of benefits that must be covered by all health insurance plans
C. Multivitamins
D. Sleep and proper diet

19 What preventive care and wellness programs can consumers receive in 2014 without a deductible or making a copay or coinsurance payment?

A. Annual wellness visits (checkups)
B. Vaccinations
C. Mammograms
D. Blood pressure screening
E. All of the above

20 Consumers will have to protect themselves against violations of ACA by insurers.

True or False?

21 Which of the following will guarantee that my out-of-pocket costs won't go up because of ACA?

A. Factor is moved to a specialty tier
B. I purchase health insurance on the Marketplace
C. I'm overweight
D. None of the above

Congratulations on completing the quiz! Now check your answers on page 11. And email us to report on how you did. Was it hard? Did you find your known unknowns? Unknown unknowns? We hope you learned something new. If you still have unknowns, don't hang on to them. Find the answers. Help is out there from your chapter, NHF, HFA, and other sources. Welcome to a new era in healthcare, and stay prepared for changes.

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Tracks & Trends

Nearly two-thirds, or 62%, of all bankruptcy filings in the US in 2007 were due to illness or medical bills.

ACA allows young adults to stay on their parents' plans until age 26. As of June 2012, more than 3 million young adults gained insurance coverage because of this change—a 10.4% increase in the number of insured young adults from 2010. Of the 13.7 million young adults with this source of coverage, about 6.6 million would not have had this option before ACA.

Source: www.americanprogress.org

83.7% of Americans had health insurance coverage in 2010

55.3% of this was through employment

9.8% was through direct purchase, and 31.0% was government funded (Medicare, Medicaid, military). The overlap in percentages reflects coverage by more than one type of health insurance.

Source: US Census Bureau

More manufacturers are seeking to enter the US market, and current manufacturers in the US are expanding their production into other segments. More than 10 new hemophilia products are in clinical studies, expected to come online in the next few years.

Source: *American Journal of Medicine* June 2009

15% of hemophilia patients in the US use plasma-derived products

85% use recombinant

About 31% use prophylaxis

Source: CDC

A very small group of young adults may see premium increases due to ACA's age rating and other market reforms. Data from the Census Bureau's Current Population Survey: of the nearly 47 million young Americans between ages 19 and 29, only about 3% might see higher premiums. These young adults have incomes that may be too high to qualify for federal subsidies to fully offset the premium increases.

Source: www.americanprogress.org

The **US** is the only wealthy, industrialized nation that does **not** have a **universal** healthcare system.

Disconnect!

Almost half the public polled reports hearing "nothing at all" about whether their state will participate in the state Marketplace; about 20% have heard "a lot" or "some." When asked what they know about their governor's decision on whether to expand Medicaid in their state, the vast majority say they haven't heard enough to know what that decision is.

Source: Kaiser Family Foundation, March 2013 Tracking Poll

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

Q: I'm a bit overwhelmed. What are my choices under the new healthcare law, and where do I go for help?

A: It's easy to feel overwhelmed. The Affordable Care Act (ACA) was implemented in 2010, and all the provisions aren't yet in place; some won't be until 2016 and beyond.[1] So much is changing! What if you need to buy an insurance policy for the first time, because everyone will be required to have insurance in 2014?[2] What if you have an individual policy now, but aren't sure how you'll get one in 2014? Maybe you're on Medicaid, and your state recently made changes in the eligibility requirements. Perhaps you already have insurance, but you realize that your employer has changed the policy. Where can you go to learn more about these changes? ACA has created new options for healthcare coverage. It's important to understand *all* your choices. Let's look at some ways to learn what your options are and find help deciding which is best for you.

Learn about Medicaid Expansion. ACA allows for an expansion of eligibility for Medicaid—meaning that more people can enroll. But not all states will expand Medicaid.[3] Will yours? Learn what your state's eligibility requirements will be in 2014. Do an Internet search for your state's Medicaid website, and once there, look for a section on *eligibility*. Your local hemophilia organization or HTC might also know if your state is expanding Medicaid. Or find the phone number for your state's Medicaid office, and call to ask if there is an expansion and whether you are eligible.

These websites may be helpful:

- www.statehealthfacts.org *(click on your state, then Medicaid and CHIP, then eligibility or reform)*
- www.cbpp.org *(to learn if your state is expanding Medicaid)*

Learn about Your State's Health Insurance Marketplace. The new Health Insurance Marketplaces are web-based programs that allow you to compare and "shop" for an individual insurance policy that best meets your needs. The Marketplaces will be ready to enroll people in October 2013 for coverage that will begin in January 2014.[4] Small businesses will also be able to use the Marketplaces for employee coverage.[5] To learn about your state's Marketplace, visit www.healthcare.gov or call your state's department of insurance. Healthcare.gov is available in English and Spanish.

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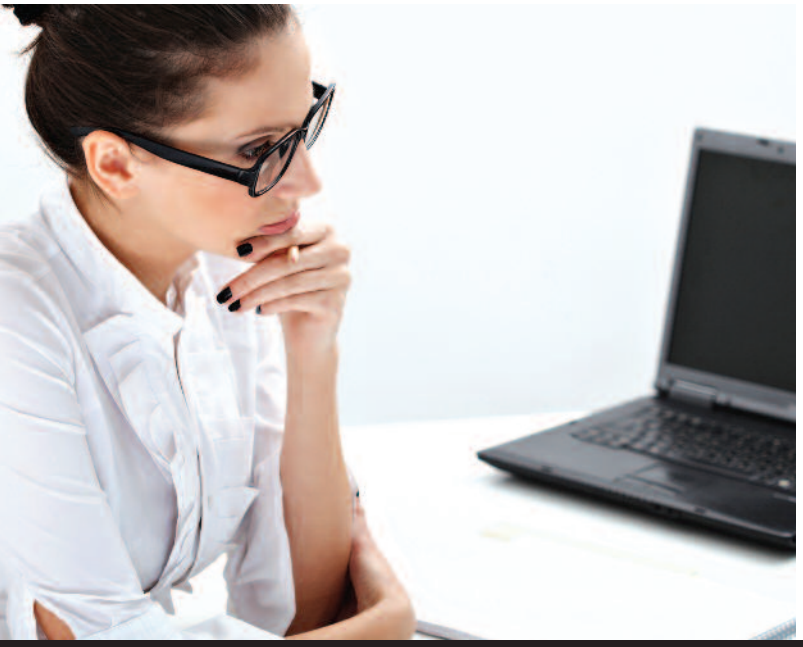


More resources for learning about healthcare reform and healthcare coverage options

- Your HTC social worker
- Your local hemophilia organization
- National Hemophilia Foundation (www.hemophilia.org)
- Hemophilia Federation of America (www.hfa.org)
- Patient Services, Inc. (www.psi.org)
- The manufacturer of your factor, or the specialty pharmacy that provides your factor
- Kaiser Family Foundation (healthreform.kff.org)
- Families USA (www.familiesusa.org)

Real Life

Advocacy: Coast to Coast

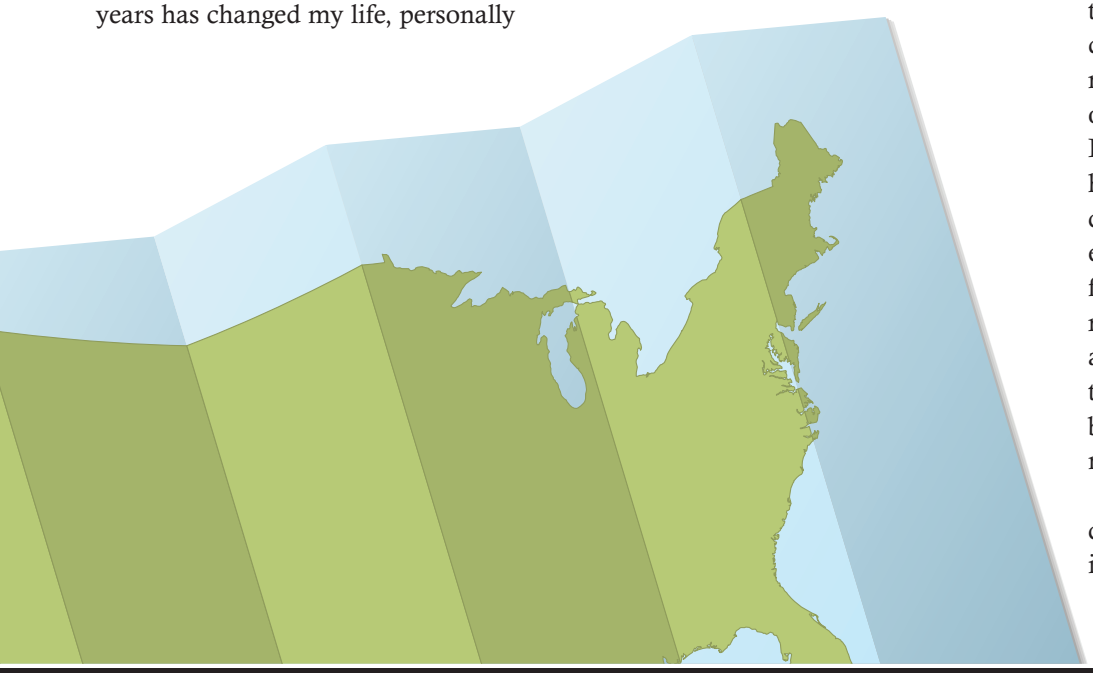
Kate Muir


Duncan Muir

Summers spent as a child in New England with my father were blissful, with one exception. "It *really* won't hurt much," he would say with his jack-o'-lantern eyes smiling at me, holding a needle and syringe in one hand while gently reaching out to me with the other. I was always the last of my eight siblings to receive our regular tetanus booster from our physician father. At this age, I feared nothing more than a needle. No one in my family, including myself, could have imagined that twenty years later, I would be adept at using needles to infuse lifesaving factor into our infant son, who had been diagnosed with severe hemophilia A—and adept at advocacy.

Although it was my father who inspired me to pursue a career in healthcare, it was my young son's matter-of-fact bravery that directed me toward health policy and advocacy. What I have learned since those early years has changed my life, personally and professionally. My college coursework in health education grounded me in the belief that we all have the capacity to be responsible for our health. We must increase our awareness and knowledge of areas that positively influence our health: exercise, balanced nutrition, and disease prevention. Becoming our own best advocate in our healthcare is not only a right—it's a privilege that we often must challenge ourselves to accept.

Hours following our five-month-old son's diagnosis with hemophilia, amid the swirl of information that flooded our thoughts and emotions, my husband Craig and I were reassured that he was born at a fortunate time—March 1985, exactly when the FDA mandated heat treatment of all blood products. The significance of this wasn't immediately apparent to us on the East Coast, in the sparsely populated state of Vermont where our son was born, and where the diagnosis of hemophilia was made infrequently. Three years later, we returned to the West Coast to pursue careers in the San Francisco Bay area, where I had grown up with my mother. The dedication and energy of the local hemophilia chapter there, as it rallied around countless individuals and family members infected by HIV, brought this harsh reality home.



As we grew steadily in our knowledge of managing a bleeding disorder in an active youngster, our new friends shared with us their experiences, cementing our compassion and commitment to the entire community. It made no difference that my son was HIV negative as I joined a support group of women whose sons had developed HIV/AIDS. I was drawn to their grace, humor, and wisdom. Their warm hugs comforted me as I watched them endure indescribable grief at each son's funeral. My gratitude was replaced by a resolve to seek answers, accountability, and assurance that a devastating tragedy of this magnitude would never be repeated. There was no doubt in my mind then that I was an advocate.

Advocacy thrives on effective communication. I had learned the importance of public speaking in high

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Q What does *managed care* really mean?

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

Michelle Rice
Director of Public Policy
National Hemophilia Foundation (NHF)

First I want to make one point: managed care is not bad! Managed care can work well for patients with bleeding disorders as long as they have access to their hemophilia treatment center (HTC) for medical care, have access to the factor product prescribed by a physician, and have some choice in specialty pharmacy provider. Patients must pay attention to these key details when selecting a plan.

The meaning of managed care may differ depending on whether you're a patient, physician, or health insurance carrier. The term generally refers to various techniques designed to improve quality of care while reducing the cost of providing health benefits.

Managed care has been around since the early 1970s. We often associate it with health maintenance organizations (HMOs), though most health plans now incorporate some aspect of managed care. Insurers may use the following methods to manage the costs, use, and quality of healthcare services for their plan members:

- Offering limited or specific provider networks
- Requiring plan members to choose a primary care provider (PCP)
- Establishing a utilization review to evaluate the appropriateness and quality of care provided
- Requiring a referral from a PCP to see a specialist
- Emphasizing preventive care
- Offering financial incentives that encourage patients to use care efficiently (reduced copays or deductibles for certain services and/or providers)

Why does this matter to people with bleeding disorders?

Managed care plans can be less expensive for patients. Often the copays and deductibles are lower than in other plan designs. But cost shouldn't be your sole concern when choosing a plan. Equally important are *benefit design* (what services are covered?) and *network adequacy* (who can you visit to receive benefits?).

NHF is concerned, first, about limited provider networks and referrals as cost-control methods. If you use a provider who is not contracted with your health plan (out-of-network), you may be responsible for a greater percentage of that cost, possibly even 100%! Plans sometimes make exceptions to allow members to use out-of-network providers, but only with a referral from a PCP, and coverage isn't guaranteed. One question you need to ask: is your HTC in-network?

A second concern is the way managed care plans are reimbursed by the entities—employers, Medicaid, or Medicare—that contract with them.

Capitation is a payment method in which the health plan is paid a contracted rate for each member assigned to it, often called a "per member, per month rate," regardless of the number or kind of services provided. The rates are usually adjusted for age, gender, illness, and regional differences. The plan is paid a certain amount per person per month to cover *all* of the person's healthcare costs, including hospitalization, inpatient and outpatient care, and pharmacy costs. For example, a state Medicaid program pays Plan X $800 per month for every member enrolled in that health plan. Plan X has 1,000 participants, so it receives $800,000 per month to provide for their care.

The idea is that because not all participants will be receiving monthly services, the money saved can be used to offset the higher costs of those who use more services. Because people with hemophilia typically *do* receive monthly services that can be very expensive (certainly more than $800), the costs for these plans could quickly exceed the reimbursement the plan receives from the state.

A third concern is the long-term viability of plans that receive a higher-than-average number of high-cost patients—such as those with hemo-

philia. NHF believes this could lead to an interruption in continuity of care. We are currently working with health plans to help identify ways to insure that patients continue to have access to care without interruption.

Despite these concerns, remember that managed care plans are not a bad option, and they may be less expensive, as long as you do your homework *before* signing up:

- Check to see that your healthcare providers are considered in-network.
- Understand the plan's rules for prior authorization and referrals.
- Review the plan's drug formulary to make sure your brand of factor is covered.
- Find out if factor is covered under major medical or pharmacy, and who the plan's authorized factor providers are.
- Find out if you're covered if you go out-of-network, and what your cost share will be.
- Read the provisions of the plan, and contact your HTC social worker for help.

Dana Kuhn, PhD
President/Founder
Patient Services, Inc. (PSI)

Managed care means having professional medical personnel manage your medical care, providing the best of services, justifying services, offering plans of care, and appropriately containing costs surrounding your well-being.

Recently, many states have chosen to use managed care plans to provide Medicaid services. This is often called "managed Medicaid." However, there are discussions within the states about making managed Medicaid more like private insurance. To more efficiently administer the state and federal funds used to propel managed Medicaid, it's possible that the benefits design would include primary care physicians (PCPs) as gatekeepers in determining prior authorizations, referrals to specialists, and referrals for needed procedures or tests. There will be an awareness of containing costs in order to maximize the increased number of beneficiaries who will qualify for the Medicaid expansion of benefits under the Affordable Care Act (ACA).

Managed Medicaid may follow the same benefit design as private insurance, which requires beneficiaries to be responsible for cost sharing (for example, copayments, coinsurance, and out-of-pocket expenses).

Learn More about Managed Care

NHF's Insurance Toolkit has definitions of managed care provisions: www.hemophilia.org

Your state department of insurance commissioner's website

Medicaid Health Plans of America: www.mhpa.org

Government websites, especially Centers for Medicare and Medicaid Services: www.cms.gov

Your state Medicaid website for the expansion and development of programs

Right now, most patients we are assisting at PSI may not be aware of the coming changes in Medicaid; but the more research-oriented patients are questioning whether states will implement the concept of managed Medicaid, and how that will impact them both medically and economically.

With managed Medicaid, we can expect models of expanding the benefit to more people, yet applying methods of cost savings to accommodate the increase in applicants to Medicaid. It's inevitable that some sort of cost sharing will be implemented. The question is, will beneficiaries be able to afford the cost sharing?

Peg Geary, LCSW
Clinical Hemophilia Social Worker
New England Hemophilia Center

When Massachusetts introduced its healthcare reform project in 2006, the goal was to strive toward universal insurance coverage for our residents. Various managed care plans have arisen from the need to provide services at lower costs. When ACA takes effect for the rest of the country, managed care plan options may be widely offered. Consumers should be informed about these options and weigh the pros and cons of the plans.

Managed care generally refers to insurance plans that consist of HMOs, PPOs (preferred provider organizations), or POS (point of service) plans. In response to healthcare reform, Massachusetts offered residents a spectrum of insurance options through state-funded and private plans, at sliding-scale fees; many were managed care plans.

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Healthcare Insurance Quiz Answer Key

1. Answer: C

There really is no free lunch, so you won't be dining out during visits to your doctor.

But middle-class Americans will get a tax credit on their health insurance premiums, beginning Jan. 1, 2014. "Middle class" means individuals and families earning between 100% and 250% of the Federal Poverty Level (FPL)[2] who are not eligible for other affordable coverage. Qualifying individuals and families can spread the tax credit out over the year so that their premium payments are reduced each month, rather than receiving a lump-sum refund.

And as of Jan. 1, 2014, ACA prevents insurers from canceling or limiting coverage for those who want to participate in clinical trials of new drugs intended to treat their condition. This part of the law applies to all clinical trials.

But ACA doesn't stop there: as of Jan. 1, 2014, new plans and existing group plans are prevented from imposing annual limits on the amount of health coverage an individual may receive. This will end the phase-out process for annual limits that started in Sept. 2010 with an annual limit of $750,000 and reached $2 million for Sept. 2012 through Dec. 2013.

Finally, insurers can no longer discriminate against people with pre-existing conditions or of a specific gender by denying or limiting health coverage. ACA prevents insurers from capping or canceling coverage just because a family member gets sick, suffers from a disease, or is in an accident.

2. Answer: True

The US government can make you purchase health insurance; this is called the *individual mandate*. You may face a penalty if you don't. The US Supreme Court ruled that the penalty is considered a tax, and Congress has the right to impose a tax on US citizens. So as of Jan. 1, 2014, most individuals and their dependents must have "minimum essential coverage" or pay a penalty for failing to comply with the law. According to ACA, minimum essential coverage includes individual market policies, job-based coverage, Medicare, Medicaid, CHIP, TRICARE, and certain other coverage (for example, state health benefits risk pool, recognized by the secretary of Health and Human Services [HHS]). So you can't just have dental insurance, and your pet insurance won't cut it.

There are exceptions to who must have coverage. These include people with a religious exemption, US citizens not living in the States, non-US citizens living in the States and any US possession, and people who are incarcerated. Additional exceptions include members of Native American tribes; people without coverage for less than three months; people whose contribution (premium) exceeds 8% of their income; people whose income falls below the federal income tax filing threshold; and people who receive a hardship waiver from the HHS secretary.

3. Answer: E

You and your dependents must have health insurance from at least one of the following: a government-sponsored plan (Medicare, Medicaid), an employer-sponsored plan, a plan purchased through the future Health Insurance Marketplace, grandfathered plans,[3] or a state health benefits risk pool plan (not the same as the temporary national high-risk pool currently in place until Jan. 1, 2014). The plan you choose must provide at least minimum essential coverage, and the plans listed here meet that definition.

4. Answer: B

No one wants to arrest you—that will cost the government even more money. You'll have to pay a penalty if you are not insured for 2014 and forward. If you don't meet the exceptions listed in answer 2, here's how you'll have to pay. The penalty for noncompliance is the greater of these two options:

- A flat dollar amount assessed on each taxpayer and any dependents. There is a phasing-in of dollar amounts as people work to find health insurance. In 2014 the penalty amount is $95 per taxpayer and any dependents, $325 in 2015, $695 in 2016, and adjusted annually for inflation after that. The penalty amount is reduced by half for any dependents under age 18. There is a cap on the flat dollar amount penalty: 300% of the annual flat dollar penalty amount a family would owe due to failure to comply with the law.
- A percentage of an individual's or couple's (if filing jointly) income. This is the amount of an individual's household income that exceeds an applicable filing threshold each tax year. This filing threshold includes the personal exemption amount as defined by the IRS plus a standard deduction amount: 1.0% in 2014, 2.0% in 2015, and 2.5% from 2016 on.

5. Answer: E

The Health Insurance Marketplace will be a web-based service where individuals and small businesses can compare and ultimately purchase health insurance. In each state, the Marketplace will offer health insurance options to individuals under the American Health Benefits Exchange, and to small employers (fewer than 50 or 100 employees, depending on the state) under the Small Business Health Options (SHOP) Exchange. With the Marketplace, individuals and businesses will be able to compare all insurance options based on price, benefits, quality, and other key plan features.

ACA requires every health insurance plan available in the Marketplace to offer comprehensive coverage, including doctor visits, hospital stays, wellness and prevention services, and medication. This kind of plan is a Qualified Health Plan (QHP). A QHP is a plan that meets certain minimum standards, including offering all essential health benefits;[4] meeting marketing requirements that do not discourage enrollment in the plan by people with significant health needs; implementing a quality-improvement strategy; using a uniform enrollment form; presenting benefits and plan options in a standardized format; and meeting other applicable quality and reporting requirements.

Under ACA, the Marketplace is required to provide a variety of customer service tools, including a website, a toll-free hotline, and special assistance agents called *navigators*. These tools and navigators are all intended to help consumers determine whether they're eligible for any financial assistance. ACA also requires the Marketplace to tell consumers if they're eligible for coverage through a state's Medicaid or CHIP program.

ACA will also offer two types of financial assistance for Marketplace plans. The type and amount of assistance will be based on the amount of money you make and the size of your family. The first type is Premium Assistance Credits, refundable tax credits that can be claimed at the time an individual purchases a QHP. The second type is Cost-Sharing Subsidies, federal payments that reduce the out-of-pocket spending limits to certain categories of Marketplace health plans by up to two-thirds. For both types of financial assistance, people with lower incomes will receive more credits to help them pay for coverage. When you fill out your Marketplace application, you'll find out how much you can save based on your income and family size. According to www.healthcare.gov, most people who apply will qualify for lower costs of some kind.

6. Answer: E

Only qualified individuals and employers can purchase plans through the Marketplace. A qualified individual is a US citizen or legal immigrant who is not incarcerated at the time of enrollment. A qualified employer is a small employer who chooses to make all full-time employees eligible for one or more QHPs offered through the Marketplace.

7. Answer: A

The Marketplace will offer four categories of health insurance coverage: Bronze, Silver, Gold, and Platinum. Each plan is based on an actuarial value, or an average portion of eligible healthcare costs that each plan will cover. For example, if a consumer has a Silver plan, she would be responsible for 30% of covered healthcare costs and the insurer would be responsible for the remaining 70%. Precious metal actuarial values: Bronze 60%+, Silver 70%+, Gold 80%+, Platinum 90%+. The actuarial value for each category is an average, not the actual cost, so a consumer's portion of the cost may be higher or lower.

8 Answer: False

Each state can choose whether to (1) operate its own Marketplace; (2) partner with the Department of Health and Human Services to run some of the functions of the Marketplace; or (3) have a Marketplace fully supported by HHS. A final list of state-run and HHS-supported Marketplaces will be available in Oct. 2013, when consumers can begin to enroll in Marketplaces. No matter what option your state chooses, in Oct. 2013 you'll be able to compare health insurance plans in the Marketplace to find one that meets your coverage needs and budget. To learn the status of your state's Marketplace: www.healthcare.gov/marketplace.

9. Answer: D

Parents with a health insurance plan that covers children can already add or keep their children on the policy until age 26. This part of ACA applies even if the child is married, is not living with you, is attending school, is not financially dependent on you, or is eligible to enroll in an employer's plan. Now it's up to you to decide if your child has to pay a portion of your monthly premium. (Or you pay it, and your child spends his money on rent so he isn't living with you, eating your food, watching your TV, or asking you to do laundry!)

If you or a family member does get sick, you are protected from having your insurance company cancel (rescind) your insurance. Believe it or not, in some instances women had breast cancer and their insurance companies searched for errors on their original insurance applications. When an error was found, the companies canceled the patients' insurance policies. ACA now prevents this from happening.

ACA's Rate Review program is intended to help protect individuals and small businesses from unreasonable health insurance rate increases. Starting on Sept. 1, 2011, health insurers must justify any rate increase of 10% or more before the increase takes effect. This means that your insurer must convince the federal or state Rate Review board that an increase in premium rates of 10% or more is reasonable. All proposed rate hikes are posted online for public comment.

10. Answer: True

As of Jan. 1, 2014, ACA prevents new plans and existing group plans from imposing annual limits on the amount of health coverage an individual may receive. Red flags: ACA does not prevent insurers from putting annual or lifetime dollar limits on nonessential healthcare services, or on care services that do not fall under the essential benefits categories. Also, if you have purchased a grandfathered individual health insurance policy, then the annual and lifetime limits do not apply to this plan. This would be an individual plan, not through your employer, purchased before Mar. 23, 2010. Check with your insurance company if you're not sure whether you have a grandfathered plan.

11. Answer: False

ACA was designed to allow Americans with good health insurance to keep it. Currently, about 133 million Americans have employer-sponsored health plans.[5] Most large-employer plans already have comprehensive health benefits, and in 2014 these must also include all essential health benefits if not already offered. People who are self-employed or who work for small employers, for example, may find that purchasing a health insurance plan from the Marketplace is a better option than their current plan or having no plan at all.

The decision about health insurance is yours. If you work for a large company, compare options during your annual open-enrollment period. If you don't work for a large company, including a state or large municipality, explore the Marketplace and compare plans. Because the law requires you to have health insurance, find the best option you can.

12. Answer: E

Have you been paying attention? Beginning on Jan. 1, 2014, insurers can no longer discriminate against people with pre-existing conditions or of a specific gender by denying or limiting health coverage. This part of the law applies to new policies and the renewal of existing policies. ACA prevents insurers from capping or canceling coverage just because you (or a family member) get sick, suffer from a disease, or are in an accident. Also, insurers can't charge you more than other people just because you have a pre-existing condition. Beginning on Sept. 23, 2010, ACA prevents insurers from denying children (under age 19) health insurance coverage for any pre-existing condition.

13. Answer: False

As of 2011, insurance companies must spend a substantial portion of your premium dollars on medical care and healthcare quality improvement. Specifically, insurance companies serving the individual and small-group markets must spend 80% of premium dollars on medical care and services, and insurers in the large-group market must spend 85%. If insurers fail to meet these requirements, they must pay their customers a rebate equal to the amount they overspent on overhead, marketing, advertising, bonuses, and other administrative costs. Customers started to receive rebates in 2012 as insurers began to get administrative costs under control. Insurers self-report on whether they spent premium dollars properly. There is a penalty for each violation: $100 per company, per day, per individual affected by the violation. So if a company covers 1,000 people and fails to send each person the correct rebate for 100 days, this will cost the company $100,000 in fines.

14. Answer: D

As of Jan. 1, 2014, ACA expands Medicaid so that people aged 19 to 65 with incomes up to 133% of FPL can qualify for benefits. It's estimated that under Medicaid expansion, 11 million Americans will gain health insurance coverage by 2022.[6] The expansion will make it easier for men over age 18 to qualify for Medicaid—good news for young men in the hemophilia community! ACA guarantees that Medicaid recipients receive only health benefit packages that include essential health benefits (see question 18), just like private health insurance plans. The expansion does not include people who are incarcerated, non-US citizens, and those who qualify for Medicare.[7] Eligibility requirements will not change for aged, blind, or disabled individuals, children in foster care, or supplemental security insurance (SSI) cash recipients.

15. Answer: False

States have the option to expand their Medicaid programs. The US Supreme Court ruled on the constitutionality of ACA as a whole. In its ruling, the Court upheld most of the ACA provisions, including the individual mandate and Medicaid expansion. But the Court also ruled that HHS has limited the ability to enforce Medicaid expansion. As a result, the expansion of Medicaid is optional for states. The federal government cannot withhold Medicaid funding to states that choose not to expand their Medicaid programs.[8] As of May 13, 2013, 26 states are participating in Medicaid expansion, 15 states are not participating, 3 states are pursuing alternative models, and the remaining 6 states are undecided.[9] Check with your state's Medicaid office to see where your state stands on Medicaid expansion.

16. Answer: C

Donut and cookie fund-raisers might help, but hey, this is healthcare we're talking about. Someone has to help

Americans avoid the stuff that sends them to the doctor in the first place. The federal government will provide financial support to states that choose to expand their Medicaid programs to include newly eligible people. From 2014 to 2016, the federal government will pay 100% of the cost for a state to expand its Medicaid program, and 95% in 2017, 94% in 2018, 93% in 2019, and 90% in 2020 and subsequent years.

17. Answer: False

One of the goals of ACA is to improve the quality of care for all US citizens while improving the way they receive care. Provisions of ACA hold insurance companies and providers more accountable for the care they provide Medicaid patients. Some states are moving their Medicaid to a managed care delivery system, in which a state contracts with an organization to provide some or all of the Medicaid benefits to patients.[10] This move doesn't mean your coverage will be better or worse than non-managed care systems. ACA guarantees that all Medicaid patients are covered under plans that include all essential health benefits. If the switch hasn't happened already in your state, you may be switched to a managed care system regardless of your preference.

18. Answer: B

The 10 essential health benefits categories include ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care. Under ACA, all plans available through the Marketplace must include at least all 10 categories of benefits. Also, all private and grandfathered plans must provide coverage for benefits under all essential health benefits categories beginning on Jan. 1, 2014.[11] Self-insured plans do not have to cover all 10 categories of essential health benefits.

19. Answer: E

As of Sept. 23, 2010, all new health insurance plans must cover prevention and wellness services (checkups, mammograms, vaccinations) without charging a deductible, copay, or coinsurance payment. (This rule does not apply to grandfathered plans, so check with your insurance provider if you're not sure.) Forget using cost as an excuse to not have your annual checkup! ACA is requiring the coverage of preventive care and wellness services to support a push to improve the health of all Americans—which should reduce the cost of healthcare in the long term. For example, every 10% increase in funding for community-based public health programs is estimated to reduce deaths due to preventable causes by up to 7%.[12] To support this healthy goal, the Prevention and Public Health Fund (PPHF) was created under ACA. The first of its kind in the US, PPHF is a mandatory funding stream dedicated to improving America's public health. To learn more about PPHF: www.apha.org.

20. Answer: False

You won't have to go it alone against the insurance bureaucracy. Some states already offer Consumer Assistance Programs (CAPs), and ACA provides for improvements in these programs. For example, ACA guarantees you the right to ask your plan provider to reconsider a decision to deny payment for a service or treatment, in a process called an internal appeal. In an urgent situation, the insurance provider must review your request for reconsideration and issue a decision in 72 hours. If your plan provider still denies coverage, ACA provides for an external review by an independent review organization. This organization will decide whether to uphold or overturn your insurance provider's decision.[13] To find the CAP in your state and learn more about the assistance your state provides: www.healthcare.gov.

21. Answer: D

There's disagreement about whether ACA will increase out-of-pocket costs. One key area that ACA doesn't touch is insurance companies that move factor

coverage from major medical to pharmacy. When this happens, a company may put factor on a specialty tier (tier 4) along with other biologics. Under most pharmacy plans, patients must pay 20% to 33% of the cost of medication on specialty tiers. Imagine paying 33% of your annual factor cost! Watch out for this move. Legislation that prevents this from happening has passed in some states and is being considered in others, with even a bill at the federal level. Contact your chapter, National Hemophilia Foundation (NHF), and Hemophilia Federation of America (HFA) to learn what's happening in your state. Under ACA, cost-sharing limits for out-of-pocket costs (deductibles, copays, and coinsurance) are required in Marketplace plans for individuals and small businesses. But this doesn't mean that plans offered in the Marketplace will have lower out-of-pocket costs. Compare plans carefully, do the numbers, and then decide.

For large-group employer plans, there are no limits to out-of-pocket costs. Because US healthcare costs continue to rise, employers are shifting more and more healthcare costs onto employees. Employers may offer plans with lower premiums—but watch out for higher deductibles. In 2014 the average deductibles at large-employer plans are expected to increase by about 13%, to $666; and for small employers by 3%, to $1,452.[14]

Another way employers are considering reducing their costs is to charge people who are overweight more than their slimmer colleagues.[15] Six in 10 employers say they plan to impose penalties in the next few years on employees who don't take action to improve their health, according to a recent study of 800 mid- to large-sized companies.[16] For example, CVS Caremark has asked its employees to submit certain personal health information to the company—blood pressure, blood sugar levels, body fat percentage—or pay a $600 fine. Review your health plan closely. Watch for increased cost sharing. For help getting started reviewing your health plan, check out NHF's Personal Health Insurance Toolkit on its website, www.hemophilia.org.

1. Donald Rumsfeld, Feb. 12, 2002, US Department of Defense news briefing. 2. The FPL is published by the US Department of Health and Human Services and updated annually. 3. ACA defines grandfathered plans as individual and group plans in which an individual or family was enrolled on Mar. 23, 2010. For more info on grandfathered plans, see CRS Report R41166, Grandfathered Health Plans Under the Patient Protection and Affordable Care Act (ACA), by Bernadette Fernandez. 4. Essential health benefits categories include ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care. Essential health benefits may differ from state to state. 5. Source: www.healthcare.gov/news /factsheets/2010/06/ keeping-the-health-plan-you-havegrandfathered.html (accessed May 23, 2013). 6. Source: www.apha.org/advocacy/Health+Reform/ ACAbasics/#Basics8 (accessed May 24, 2013). 7. Source: www.hca.wa.gov/hcr/me/Pages/index.aspx (accessed May 24, 2013). 8. Source: www.apha.org/advocacy/Health+ Reform/court_cases/ #SCFAQ (accessed May 23, 2013). 9. Source: www.advisory.com/Daily-Briefing/2012/11/09/ MedicaidMap#lightbox/1/ (accessed May 23, 2013). 10. Source: www.medicaid.gov/ Medicaid-CHIP-Program-Information/ByTopics/ Delivery-Systems/ Managed-Care/Managed-Care.html (accessed May 23, 2013). 11. Source: http://ebn.benefitnews.com/ news/hhs-defines-essential-health-benefits-ppaca-2729494-1.html (accessed May 20, 2013). 12. G. Mays and S. Smith, "Evidence Links Increase in Public Health Spending to Declines in Preventable Deaths," Health Affairs 30(8) (Aug. 2011), 1585–93. Available online at http://content. healthaffairs.org. 13. Source: www.healthcare. gov/law/features/ rights/appealing-decisions/ index.html (accessed May 17, 2013). 14. Source: http://thinkprogress.org/ health/2012/11/15/1194651/large-employers-lower-costs-workers/?mobile=nc (accessed May 20, 2013). 15. Source: http://onpoint. wbur.org/2013/04/09/ overweight-insurance (accessed May 20, 2013). 16. Source: http://online. wsj.com/article/SB10001424127887324600704578402784123334550.html?mod=djemalertNEWS (accessed May 20, 2013).

You can get help as you apply for and choose new insurance options in the Marketplace. The assistance will be available in a number of different ways: by *navigators*, in-person assistance personnel, or certified application counselors. In addition, agents and brokers can also help consumers enroll in new insurance options.[6] Talk to your HTC social worker or local hemophilia organization to see what help is available in your state.

Ask about Employer Coverage. Will your employer offer healthcare coverage in 2014? Check with your human resource department or someone at your company who is in charge of health insurance.

Check Out Dependent Coverage. If you are under age 26, you can stay on, or get on, your parent's plan.[7] Does your parent have a private health insurance plan? What type? What does it cover? When you turn 26, you will no longer be allowed to stay on a parent's plan. Get ready now for the time when you must transition off a parental plan. (See page 3 on transitioning to your own health insurance plan.)

Know All Your Options. You might have options that didn't come directly from ACA—they've always been there. And you need to consider all options. For example,

- Does your state have a hemophilia program or chronic disease program that can provide healthcare coverage for you? Ask your HTC social worker to learn about programs in your state.
- Can you get coverage on a spouse's plan?
- Are you eligible for Medicare? Typically, people over age 65 or those with a disability will qualify.[8]
- Can you buy an individual plan? In 2014, a health plan can't deny you a policy because of a pre-existing condition.[9] Look in the phone book or search the Internet for a health insurance broker.
- Have you looked at the National Hemophilia Foundation (NHF) Insurance Toolkit to help you compare plans? Find it at www.hemophilia.org (go to the Advocacy tab and scroll down) or call 212-328-3700.

The array of options under the new healthcare reform laws can be overwhelming, but there are lots of resources to help you understand your choices and decide on a healthcare plan that will give you the coverage you need as a person with a bleeding disorder.

Elizabeth has worked with the bleeding disorder community for five years. She's been in the healthcare industry for over twenty years, and is passionate about helping people with chronic conditions get the healthcare coverage they need.

1. www.healthcare.gov/law/timeline/full.html (accessed Apr. 29, 2013) p. 1. 2. www.healthcare.gov/law/timeline/full.html (accessed Apr. 29, 2013) p. 8. 3. www.kff.org/medicaid/quicktake_medicaid_in_2013.cfm 4. http://cciio.cms.gov/resources/factsheets/state-marketplaces.html p. 1, (accessed Apr. 29, 2013). 5. www.healthcare.gov/law/timeline/full.html p. 7, (accessed Apr. 29, 2013). 6. http://cciio.cms.gov/resources/files/marketplace-ways-to-help.pdf (accessed Apr. 29, 2013). 7. www.healthcare.gov/law/timeline /full.html p. 3 (accessed Apr. 29, 2013). 8. www.healthcare.gov/using-insurance/ medicare-long-term-care/index.html (accessed Apr. 29, 2013). 9. www.healthcare.gov/law/timeline/full.html p. 6 (accessed Apr. 29, 2013).

Community Forum *from page 10*

Most of our state's hemophilia treatment center (HTC) patients have some type of managed care plan. Although the thought of an insurance company "managing" one's healthcare may seem scary, there are many benefits. First is cost. Managed care plans contract with a network of medical providers and organizations for services, so they keep their costs low. In turn, copays and deductibles are usually low. As a result, more employers are offering HMOs to workers. However, to achieve these lower costs, the plans typically enter into mandated contracts for care, resulting in a more limited network of providers. For someone with hemophilia, this may mean a change in home care vendor or specialty pharmacy that provides factor products.

My regional HTC colleagues and I have had mainly positive experiences with managed care plans. Consumers are generally happy with the level of care and low cost. Most HMOs also provide case management services, which has helped foster advocacy for people with hemophilia and commitment to quality care for their special needs.

Managed care plans are viable options for people with hemophilia. If you're offered a choice of managed care plans, remember to review the benefits and provider network that each plan provides, as already outlined by Michelle.

Transitions *from page 3*

What You Need to Do, Fast and Furious

Get a job with insurance. It's an economic jungle out there. Most Americans have private health insurance through their jobs. But if you are between ages 19 and 25, you're in the group with the nation's highest unemployment rate. You're also more likely to have a low-wage job without benefits. Bummer.

And smaller businesses may drop their plans and expect employees to use the Health Insurance Marketplace (see next section) or get the government to pop for some of the cost. But the good news, again, is that you will not be discriminated against due to your pre-existing condition.

Check out the Health Insurance Marketplace. The Marketplace is the new web-based program in each state where individuals can purchase health insurance.

Beginning October 1, 2013, the Marketplace will allow you to plug in some vital medical and personal information, your medical history, and cost constraints; you'll then get a list of insurance plans in your state that meet your needs and budget. You can choose a plan based on cost versus benefits.

Coverage will take effect on January 1, 2014. For young adults with hemophilia, some benefits absolutely *must* be covered: factor is key. Check each plan carefully to make sure the plan you choose covers factor. Use the Marketplace customer service options to help you figure this out.

Explore the Medicaid expansion. My son once thought that Medicaid was the public safety net that would cover him, no matter what. Not so! Currently, Medicaid mainly covers children and low-income adults who have special needs. ACA includes a Medicaid expansion, starting in 2014, to cover single adults with incomes up to about $15,000. This expansion is designed to account for about half of the 30 million people expected to gain insurance coverage under ACA.

One glitch: the federal government can't force states to expand their Medicaid programs. And states like that a lot, because Medicaid is often their highest single budgetary item. Will your state participate in the expansion?

The Place Beyond the Pains

Help is available beyond employment, the Marketplace, and Medicaid. Starting in 2014, if you earn below a certain income level, you will qualify for financial assistance. The lowest earners shouldn't have to pay more than 2% of their income toward insurance premiums for mid-level plans; earners at the high end would have to contribute 9.5%.

For example, if you earn less than $43,000 and your job doesn't offer affordable coverage, you may get tax credits to help pay for insurance in 2014. For instance, a single 26-year-old earning $16,000 might pay $537 toward the annual premium.[3] The rest of the premium would be covered by a $2,853 tax credit.

But premiums are not the only thing you'll need to pay. Deductibles and copays could cost up to an additional $2,000 depending on how much care you need and what the parameters of your plan are.

There may also be some help with paying for factor. Know your factor brand and who makes it. Call your factor provider (your specialty pharmacy or HTC) and ask for help in contacting the manufacturer. Ask the manufacturer about a "factor savings card" or coupon. These are usually a fixed dollar amount that can be used toward out-of-pocket costs for drugs.

If you find yourself uninsured, you may qualify for factor through the factor assistance programs from the factor manufacturers. Start saving points, coupons, or whatever these programs require to build up your access to factor and hedge against insurance coverage changes.

So put down that iPhone, disconnect from Metal Gear Rising, and get going now. Speak to your HTC social worker, your home care rep, the reimbursement folks at your factor manufacturer. Visit the websites mentioned in this issue's lead article to learn more about being a young adult and transitioning to age 26. That's when the *real* insurance action starts!

1. www.demos.org/data-byte/uninsurance-rates-age-group (accessed May 17, 2013) 2. http://aspe.hhs.gov/health/reports/2011/ YoungAdultsACA/ib.shtml (accessed May 17, 2013). 3. www.healthreform.kff.org/subsidycalculator (accessed May 17, 2013).

school, where I crafted many speeches on index cards as I participated in student government and speech contests sponsored by local service organizations, but all that seemed distant and trivial now. Yet this early experience proved invaluable, as I gained confidence to pursue leadership positions in the Northern California Hemophilia Foundation, Hemophilia Council of California, and ultimately the board of directors of National Hemophilia Foundation. We would need to prevail over our anger, fear, and grief as a community to support one another and unify our voices in the halls of Congress, the FDA, and the CDC.

Science and technology may now dictate how to prevent such deadly contamination of the blood supply, but in the 1980s it was in part the failure of essential, collaborative leadership and communication that lowered a level of government scrutiny that should have been in place. From every angle and organization, the hemophilia community would not stand down. Our community pushed through the passage and successful funding of the federal Ricky Ray Hemophilia Relief Fund Act in 1998[1]—a historic and unprecedented feat for a small and rare disease group, and an example of advocacy at its finest.

By 2007, healthcare reform was on a sure path to implementation in Massachusetts, where my family had been living since 1994. Fortified by bipartisan support in the state legislature and prioritized by a Republican governor, this landmark template would become a cornerstone of the Affordable Care Act (ACA). Those of us on the Advocacy Committee of the New England Hemophilia Association were advised to focus our efforts on influencing the policy of a network of providers being developed to comprise the "exchange" of affordable, quality health insurance plans. We were asked to provide expert testimony about living with a rare chronic disorder in the state, and about the essential need to maintain adequate access to comprehensive, state-of-the-art healthcare. Securing the choice of costly drug therapies in an emerging climate of cost containment was a critical component of our position, because there are no less expensive generic drugs to replace factor products. As our own best advocates, it was up to the hemophilia community to educate legislators and department leadership about the increased cost of compromising the care of complex bleeding disorders.

When I walk through the capitol building in Sacramento today, after another coastal migration West three years ago, I think of my maternal grandmother Virginia Cameron Foran, who died unexpectedly the year I was born. She pioneered advocacy for women in California long before it was fashionable or acceptable. I feel her strength in me as I shake the hands of legislators and their staff. They are eager to understand more about living with a costly bleeding disorder, as the state prepares for the significant task of implementing ACA. The glint in my son's eyes is unmistakable as we walk the halls of Congress in Washington, DC, every year together during NHF's Washington Days event. At age 28, he is self-insured as a consultant in Massachusetts. He is his own best advocate now.

Kate Muir lives with her family in Davis, California, where she and her husband Craig were students at the University of California–Davis over 30 years ago. She is a member of the board of directors of the Hemophilia Council of California (HCC) once again, after serving as chairwoman from 1992 to 1994.

1. The program was established when President Bill Clinton signed into law the Ricky Ray Hemophilia Relief Fund Act of 1998. The Act (Public Law 105-369) was created by Congress to make compensation payments of $100,000 to individuals with hemophilia who were treated with HIV-contaminated clotting factor products between July 1, 1982, and Dec. 31, 1987. Spouses and children who contracted HIV from these individuals, as well as specified family survivors, were also eligible for compassionate payment (www.hemophilia.org).

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. The CARE program helps all people living with hemophilia, regardless of therapy.

To enroll in the CARE program, contact your Baxter representative or call toll-free:
1-888-BAXTER9 (1-888-229-8379)

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