

# PEN's Insurance Pulse

Inspiring Advocacy

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## From Cradle to Medicare

### Preparing for insurance changes at each stage of life

by Laurie Kelley

Raising a child with hemophilia is daunting but doable, and over the course of twenty years, most parents succeed with flying colors. But overshadowing our lives as much as the worry of bleeds is the fear of losing insurance. Insurance pays for factor and expert medical care. It's essential to have it. Yet insurance is almost always in flux, and personal insurance needs change with different stages of life. What are these needs as you move through the stages of raising your child? How will your child's insurance needs change as he becomes an adult, in charge of his own care? What should you know and accomplish at each stage?

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# Welcome

## PEN'S INSURANCE PULSE

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Welcome to the inaugural issue of PEN's INSURANCE PULSE, a new newsletter created to inspire families with hemophilia to advocate for better healthcare and access to care. "The Coming Storm," as we dubbed the rapidly changing hemophilia insurance landscape in 2005, has never really dissipated. Instead, we have seen even greater change in industry, in insurance, and in the ways that hemophilia care and coverage are viewed and reimbursed. We must now learn to live with permanent monitoring by payers, constant reimbursement cuts by states, and continued consolidations by corporations.

INSURANCE PULSE is designed to offer brief, power-packed articles on what's happening right now, how changes will affect you directly, and what you can do to preserve a high standard of care. Don't wait until disaster strikes! We want you to understand your insurance policies, be aware of your options, and be prepared for changes. Our first feature article, "From Cradle to Medicare," maps out the life cycle of hemophilia



insurance as a guide to handling the next steps in your life.

Our gratitude to Baxter BioScience for proposing the idea of this newsletter, and for funding this special issue of PEN. If you like it and want to see future issues of INSURANCE PULSE, please let us know. Your feedback will determine whether we continue this publication. Email, call or write, and tell us what you think. Knowing what you want and why you want it — and then taking action — is the beginning of advocacy.

*Laurie*

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

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

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## Anxious Times

by Kevin Correa

Unless you've given up TV, radio and newspapers, you haven't escaped the pervasive media coverage of our turbulent economy. *Over 5 million jobs lost in the US since the beginning of 2008. Unemployment hits a 25-year high. 663,000 jobs lost in March alone.*

Economic turmoil has many people worried about job security, and for people with hemophilia, that naturally leads to anxiety over insurance. Without insurance, you're responsible for paying the high bills for medical expenses like factor and home therapy.

Now, more than ever, you should have a firm understanding of your insurance coverage, paying particular attention to the circumstances and timing under which your policy might expire. Everyone — not just those facing potential layoffs — should take time to review their policies.

Sean, a 26-year-old college student with hemophilia, has 18 months left until he graduates. He anticipates that he'll be offered insurance by an employer after graduating, but his current insurance expires in four months, and he's scrambling to find insurance that will bridge this coverage gap. "I'm just trying to survive until then," says Sean. He is justifiably concerned.

In one sense, Sean is fortunate because he knows exactly when his insurance will expire and can plan ahead. But that doesn't make the process any less stressful.

Take the time now to build a firm understanding of your existing policy. Some common reasons you might lose your insurance:

- a job layoff
- a change of employer that entails a change of insurance carrier
- you reach a lifetime maximum
- as a dependent, you reach a designated age and are no longer covered by a parent's policy

Although job layoffs are often unpredictable, there are instances — like Sean's — when an insurance expiration looms, and you can get prepared.

### When You Lose Your Insurance

The following programs can help individuals and families when they lose insurance.

#### *Consolidated Omnibus Budget Reconciliation Act*

COBRA was established to allow you to continue the insurance coverage you



received through an employer. The downside to COBRA is that it is temporary and expensive.

#### *Public Assistance*

All states have programs for people who can't afford medical expenses; several have assistance programs specifically for hemophilia. If you can't afford the high cost of COBRA coverage, you may qualify for a public assistance program like Medicare, Medicaid, Supplemental Security Income, or State Children's Health Insurance Program (SCHIP).

#### *Other Alternatives*

Patient Services Inc. (PSI). This non-profit provides people with chronic disorders temporary insurance coverage while they transition between policies.

Free Factor Programs. Some manufacturers offer free factor as part of programs like these:

- coupon or credit program
- research trials
- free trials
- compassionate care programs

Each program has specific guidelines and eligibility — for example, registering

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### The Diagnosis

The hemophilia diagnosis creates emotional turmoil in almost every family, turmoil that takes time to resolve. As a parent, you're preoccupied with emotionally accepting the diagnosis, while visiting the hospital, getting blood tests, and learning new medical jargon. You must choose a blood-clotting product.

### Questions to Ask Your Insurance Company

- Are there special restrictions or requirements for care at an ER?
- Does this policy cover out-of-state medical services?
- Does this policy cover out-of-country medical services?
- How do I appeal a decision made by the insurance review board?
- Is there an open enrollment period?
- Does the company contract with a disease management company?
- Am I entitled to receive EOBs?
- Does the company use specialty pharmacies?
- What is the monthly premium or portion of the premium I must pay?
- What is the annual deductible per person?
- Are there any co-payments?
- What is the annual co-insurance?
- What is the lifetime maximum?
- Will prescription claims be paid at 100% after I meet annual out-of-pocket expenses?

Soon, you're learning to deal with infusions and identifying symptoms of bleeds. You're focused on finding community support, learning the hemophilia ropes. It may seem like a distraction to study insurance issues when you have a baby to love and protect. A million-dollar lifetime limit seems far away.

Of course you realize that you may have co-pays, perhaps \$10 or \$20, every time you visit the doctor or purchase medicine. And you may know that whenever you have a medical procedure or order factor, you generate an explanation of benefits (EOB). You may thank your lucky stars simply to have insurance, an HTC and factor — but be smart!

#### What you need to know:

- What type of insurance do you have: private or public?<sup>1</sup>
- If private, what policy is offered: Traditional? PPO? HMO?
- Is your HTC in-network or out-of-network?
- Do you need a referral from your primary care physician to see your HTC hematologist?
- Is factor covered? How much of it is covered? Are all products covered?
- Can you choose where you get your factor: Home care company? Payer specialty pharmacy? Your HTC? Will your insurance cover and pay for factor distributed by each of these companies?
- Will factor be shipped to your home?
- Is there an annual deductible on your child's policy? How much is it?
- Is there a lifetime maximum, or cap, on your child's policy? How much? What

medical services and products are applied to the cap?

- What is your co-pay for doctor's visits, factor shipments, ER visits?
- Is factor covered under your medical benefit or your pharmaceutical benefit?<sup>2</sup>

#### What you need to do:

- Register with your manufacturer's patient assistance program.
- Read your insurance policy carefully. Know all of your options.
- Record all phone conversations with your payer: include name, date, time.
- Put all important information in one easily accessible place.
- Be sure you receive your EOBs after each shipment or medical procedure.
- Meet with your HTC social worker to discuss the basics of insurance.



1. Health insurance is available from private insurance companies like Blue Cross Blue Shield, Cigna, and Aetna. These companies sell policies to employers, who then cover their employees' medical expenses. Policies are also sold to individuals. Group and individual policies cover roughly 65% of Americans with hemophilia. Public programs include Medicaid (low income) and Medicare (age 65 and older and people with certain chronic conditions). 2. The medical benefit (also called major medical) covers all clinical services, such as doctor visits, diagnostic tests, and surgery. The pharmacy benefit covers outpatient drugs. Either budget can have a lifetime cap. For most people with hemophilia, factor is covered under the medical benefit, which usually has a lifetime cap.

## Preschool Years

Life settles into a routine during the preschool years. By now you've mastered infusions, and you may have attempted or succeeded at home infusions. You've learned a lot about hemophilia, know your child's bleeding pattern, and know the symptoms of bleeds. If there are no overt complications, like inhibitors, chances are you've reduced clinic visits to once or twice a year. Your child may have a port. He may be in daycare or preschool, and his caregivers know how to contact you if something happens. All in all, things are pretty smooth on the hemophilia treatment front.

Things are probably smooth on the insurance front too. If you're still with the same employer as at the time of diagnosis, not much may have changed. Some families decide that one parent will stay home, which reduces insurance coverage to one policy. Others decide that both parents should work outside the home, to get secondary insurance as a backup.

### What you need to know:

- Has your coverage changed?
- What other types of insurance does your employer offer?
- When is your employer's open enrollment period (the time when you can change insurance policies)?
- How much of your lifetime cap have you used?
- What's the reimbursed per-unit price of factor?
- How much factor does your child use per month, estimated?

### What you need to do:

- Register with your manufacturer's patient assistance program.
- Read your insurance policy carefully every year.
- Ask your human resources department if any company policy changes affect your coverage.
- Continue to monitor your EOBs.
- Record every bleed and all factor usage: record lot number, IUs, brand, date used.

## School Years

Your child is now age seven to ten, and he's ready to learn self-infusion. As he has grown, so has your factor budget. More weight and more activity mean more factor usage. You've probably established a factor log (possibly electronic) to record relevant details of each infusion. Logs are important for insurance purposes: at some point you may need to defend usage with documentation.

In terms of insurance, you may have some big changes. If you now have another child with hemophilia in the family, you'll have double the paperwork and monitoring. You may be ready for a job change, and this usually means a new insurance policy. Or your employer may have switched policies.

### What you need to know:

If you are still with the same employer:

- Has your coverage changed?
- How much of your lifetime cap have you used?

If you have a new employer or are considering a new plan:



- Does that new plan use a formulary?<sup>3</sup> Is your brand of factor on it?
- Is there a pre-existing condition waiting period clause?
- Is there a lifetime maximum?
- Does the policy include catastrophic illness coverage?
- How does the Health Insurance Portability and Accountability Act (HIPAA) protect you against pre-existing condition clauses?

### What you need to do:

- Register with your manufacturer's patient assistance program.
- Continue to read your insurance policy carefully every year.
- Read hemophilia magazines, such as NHF's *HemAware*, to stay on top of insurance changes. Go to the websites of the NHF or HFA to stay on top of current legislative issues that may impact your health insurance.
- Consider joining your state hemophilia group to help protect hemophilia insurance.
- Keep your log of all infusions accurate and current.

3. A formulary is a list of prescription drugs that are approved and covered by an insurance plan for its members. If your factor brand is not in the formulary, it may not be covered.

## Tweens and Teens

This is often a critical stage in insurance for two reasons. First, you may be lulled into thinking all is well. No news is good news, right? For several years, insurance paperwork and monitoring can go so smoothly. Factor is delivered with a phone call; clinic visits are reduced to once a year. It's easy for parents to slack off monitoring their EOBs, factor usage, and insurance policies. After all, you have more important things to focus on: school plays, grades, braces, transition to middle school, sports and activities, family vacations and holidays... insurance often takes a back seat.

Then boom! All the years start to add up. You must now prepare your child to transition to adult hemophilia

care when he is 18, if your HTC requires it. And if you've managed to be on one insurance plan for many years, you might be ready to cap out. Who will alert you? Usually not the insurance company. Sometimes not even your factor provider. You need to be your own watchdog.

Second, even if you have no cap, subtle changes in policy can occur that might leave you exposed, sometimes leaving your child without coverage. As your child nears 18, you must know exactly when he will no longer be covered under your policy. This overlooked rite of passage is often not even at the bottom of the To-Do list of the transitioning family, preoccupied with driver's license, college selection, and prom.

Your child may lose your coverage between ages 18 and 24, depending on school status and your particular policy. If he stays in college or trade school, generally he can stay on your insurance. It really benefits your child, no matter what, to stay in school. During his teen years, encourage his interest in school, a profession — a way for him to pay for his own insurance in future. He'll have the best coverage if he can work for the government or for a large employer.

### What you need to know:

- If your insurance policy has a lifetime cap, how close are you to reaching it?
- If your child is not attending college, at what age will he no longer be covered under your insurance policy? To what age will he be covered if he attends college? Does your policy cover your child until he is 24, if he remains a student?

## WHERE TO GO FOR MORE INFO



COVERAGE • ASSISTANCE • RESOURCES • EDUCATION

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

The CARE program is a new comprehensive insurance assistance program from Baxter BioScience, designed to help members of the hemophilia community proactively manage their health insurance situations. CARE is open to all hemophilia A patients and inhibitor patients, regardless of current therapy or insurance coverage. To enroll in CARE, contact your Baxter representative or call toll-free: 1-888-BAXTER9 (1-888-229-8379)

### Your HTC social worker

Bleeding Disorders Legal  
Information Hotline  
800-520-6154

HANDI: 800-42-HANDI

NHF: [www.hemophilia.org](http://www.hemophilia.org)

HFA: [www.hemophiliafed.org](http://www.hemophiliafed.org)

A.C.C.E.S.S.  
888-700-7010

Patient Services Inc. (PSI)  
800-366-7741

### Your factor manufacturer's factor assistance program

Your home care company  
reimbursement help hotline

Baxter's Reimbursement  
Support Team  
800-968-9937





- Under what conditions will insurance not cover him?
- Are you aware of insurance help from the hemophilia community?
- Is your child registered with factor manufacturer assistance programs?
- What's an individual policy? How does this differ from group insurance?
- What is COBRA?<sup>4</sup>

#### What you need to do:

- Register with your manufacturer's patient assistance program.
- If you decide to use COBRA, sign up as soon as possible once you receive notification from your employer.
- If you decide to purchase an individual policy, do so several months before group coverage is terminated. People with chronic disorders may be turned down. Know this as early as possible.
- Be sure to have factor on hand in case of a disruption in insurance.
- Call the Bleeding Disorders Legal Information Hotline for information concerning insurance.
- Investigate other insurance policies and options, just in case.
- Know your current policy regarding coverage of a dependent child.
- See if Patient Services Inc. can assist you in purchasing a policy for your child.

## Adult Years

Once the rocky transition years are done, your child eventually must find his own way to pay for healthcare. He has a pre-existing condition, and this could make it difficult to find a job or insurance coverage. When he applies for jobs, securing insurance as a benefit is key. If he can't find a job right away,



having a supply of factor is crucial. Factor manufacturer programs can be valuable: some offer up to 250,000 IU of factor. Some offer free factor for a specific time period. Some require coupons, so you'll need to stockpile coupons early. Baxter's CARE program (see page 6) is available for all hemophilia A and inhibitor patients, regardless of factor therapy.

Some young adults may not be able to secure insurance right away. Perhaps they did not attend college, which would have allowed for parents' coverage until age 24. Perhaps they live in an area with limited employers, or perhaps the local economy is bad. They must then look to public assistance. Medicaid is a state and federally run program that provides health insurance to low-income families. Coverage for factor under Medicaid is excellent, but you must stay at a low level of income. It's not meant to be a permanent way of life, but it could help your child until he finds a job with insurance. Your HTC social worker and the Bleeding Disorders Legal Information

Hotline can help you find out if you're eligible and how to register.

Even if an adult with hemophilia has a good job, considering the current economic climate, it's possible to be laid off. This is when COBRA can help. COBRA allows you to keep your current insurance policy after a layoff if you worked with an employer with more than 20 employees, but you need to pay the premium. COBRA is often promoted as a cost-efficient way to continue coverage. But it's been estimated that this could cost an average of \$13,000 annually for family coverage, and almost \$5,000 annually for individuals<sup>5</sup> — well beyond what most young adults with hemophilia can afford.

There are other options. If you have hemophilia and are married, you can join your spouse's plan. Or you could consider taking a job not related to your specialty or training, if it offers insurance.

And if you have a job with good insurance, know that changes in policy and coverage usually occur at the beginning of each calendar year. Be sure to know what's covered, what insurance pays, and what you pay. Basically, as an adult patient, you'll be looking at the same checklist your parents used when you were a child!

If you have a steady job with good insurance, but you're nearing your cap, you can take advantage of open enrollment. This is a certain time each year when you can make changes to your insurance plan or switch plans. New plans can mean a new lifetime maximum.

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4. The Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1986 is a federal law that allows for the temporary extension of group health coverage from your employer following a layoff, if you worked with an employer with more than 20 employees. You must pay the monthly premium, which can be expensive. 5. McQueen, M. P. "Stimulus Makes Cobra Affordable." *Wall Street Journal*. Feb 19, 2009.

# Tracks & Trends



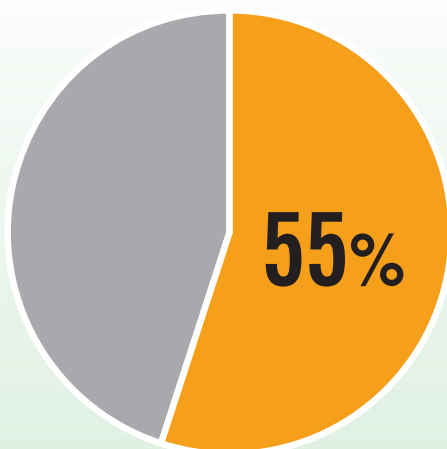
**Seven manufacturers** are registered to sell hemophilia products in the United States.

## Only 1%

of Arizona Medicaid patients have hemophilia, but they represent **20%** of Medicaid's budget.



A study by the Center of Children and Families at Georgetown University estimated that 4.1 million people, including 1.2 million children, **lost employer-sponsored health coverage in 2008**, and that 1.7 million had enrolled in public insurance programs.



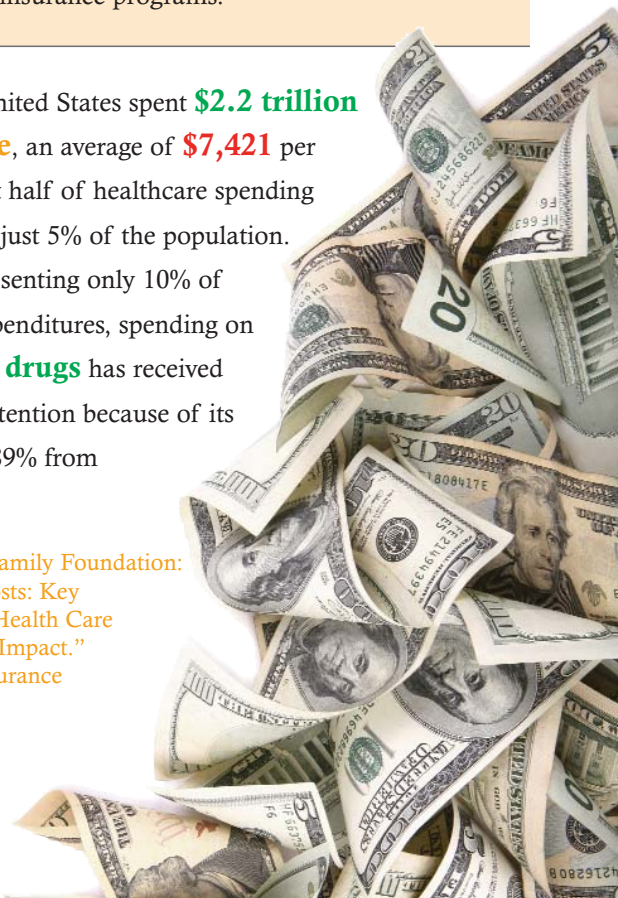
### Mad Max: Limits to Employers' Benefits

A Kaiser Foundation report found that 55% of workers with employee-based coverage had a lifetime limit in 2007, including 23% with a cap of less than \$2 million.

Source: "More Hitting Cost Limit on Health Benefits Consumers Forced To Explore Options" by Christopher Lee. *Washington Post*, January 27, 2008.

In 2007, the United States spent **\$2.2 trillion** on **healthcare**, an average of **\$7,421** per person. Almost half of healthcare spending is used to treat just 5% of the population. Although representing only 10% of total health expenditures, spending on **prescription drugs** has received considerable attention because of its rapid growth: 89% from 2000 to 2007.

Source: Kaiser Family Foundation: "Health Care Costs: Key Information on Health Care Costs and Their Impact." [www.kff.org/insurance](http://www.kff.org/insurance) March 2009.

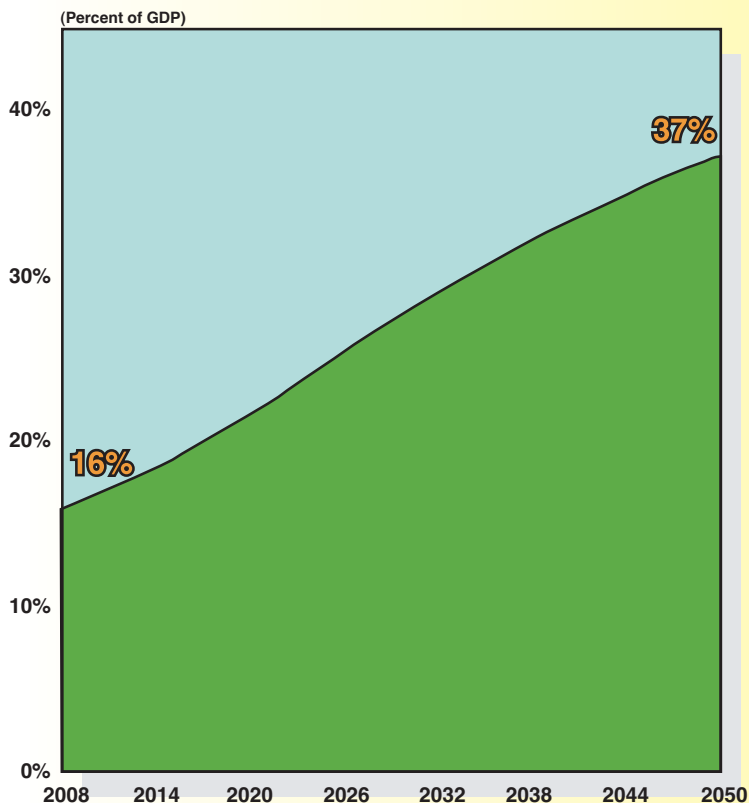






## The Greatest Challenge to a Balanced Federal Budget

### Total Health Expenditures as Percent of GDP



Spending on healthcare and related activities will account for about 17% of GDP in 2009 — an expected total of \$2.6 trillion. Under current law, that share is projected to reach nearly 20% by 2017.

Source: "Key Issues in Analyzing Major Health Insurance Proposals." Congressional Budget Office, December 2008.

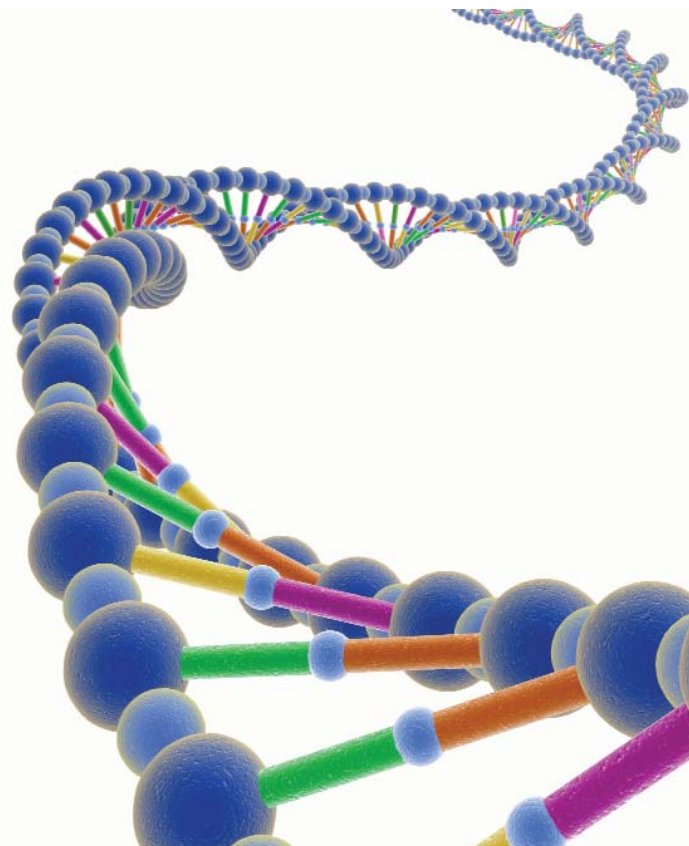
Chart source: CBO Long-Term Outlook for Health Care Spending, November 2007.

**Fewer than 10% of unemployed** workers who are eligible to continue coverage under COBRA continue to do so, largely because they can't afford it, according to a recent report by the Commonwealth Fund. COBRA costs an average of **\$13,000 annually** for family coverage.

Source: *Infusion Magazine*. March/April 2009.

In 2007, the cost of bioengineered and specialty drugs in America was nearly **\$59 billion**. Industry analysts predict this total will reach **\$98 billion** by 2011.

Source: Ostrom, Carol. "The newest generations of drugs: Who can afford them?" *Seattle Times*. August 17, 2008.



## Ask the Expert

by Mike Bradley  
Vice President of Healthcare Economics and Reimbursement, Baxter BioScience**Q: My health insurance company just assigned me a case manager. What does this person do, and how can we best work together?**

Case managers are clinical specialists, usually nurses, employed by your insurance company to help coordinate your care. Often, case managers are assigned to all health plan enrollees with certain chronic health conditions. If your insurance company does not assign you a case manager, then you can ask for one.

Your case manager is your lifeline! He or she can help you navigate the forms, requirements, and documents regarding your benefits and coverage. The more your case manager knows about hemophilia, the more he or she can help you get the best coverage and care.

If your case manager doesn't know much about hemophilia, ask to change to someone with more experience. If no

case manager has experience specifically with hemophilia, you can ask for someone who specializes in rare disorders.

You may have to educate your case manager. Your hemophilia treatment center (HTC) or specialty pharmacy may have basic educational information on hemophilia that you can share. Baxter will be introducing *The Insurance Resource Guide*, which contains a basic overview of hemophilia specifically for insurance companies. Copy this information and share it with your case manager. For a copy of the guide, ask your HTC social worker or Baxter representative.

Make sure your case manager has the names and phone numbers of your hematologist, HTC staff, and factor provider. If your case manager is unsure about an aspect of your care, such as your current treatment regimen, double check with your HTC or ask to speak with the case manager's supervisor. Remember, a case manager may misin-

terpret your care simply because he or she lacks experience with hemophilia.

Ask your case manager about the choices you can make concerning your treatment. For example, you may have a choice of factor distributors and factor concentrates. It's important to fully understand all your choices, and to strongly advocate for open access to all factor therapies and factor distributors.

When you are assigned a case manager, you can immediately start building a trusting relationship. Working together, make sure you understand your explanation of benefits (EOBs), which services or procedures need prior authorization, and your estimated costs. Your case manager can also help you track deductibles, annual limits, and lifetime cap amount, if your policy has one.

Start off on the right foot! Your case manager can be a great advocate for you and your child.

**Q: I've heard a lot about a tier 4 pharmacy benefit. What is this, and how can it potentially impact my out-of-pocket costs for factor?**

Private (commercial) insurance has two main forms of healthcare coverage: (1) the *medical benefit* covers costs such as inpatient hospital stays and laboratory and physician visits; (2) the *pharmacy benefit* covers most

drugs. Factor can be covered under either the medical and pharmacy benefit, depending on your policy. Although the pharmacy benefit covers most drugs, you may be required to pay a certain amount, or *co-payment*,

for your prescription when you pick it up. This amount depends on the pharmacy's contract with your employer or insurance company.

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# Becoming Insurance “Watchmen”

by Laurie Kelley

**K**aaren Zielinski and her husband, Alan, thought they had been through the worst of hemophilia when their son Michael was a child. Now at age 18, Michael's future looked bright, until a letter arrived that shook the Zielinskis' world.

“We got a letter [from our insurance company] in November 2008,” recalls Kaaren, a teacher in New York City. “It

read, ‘As of December 1, your son will no longer be insured through your plan; he has reached his lifetime cap.’” No insurance, and no time left to save it. Neither parent saw this coming. Stunned, Kaaren immediately called her insurer and demanded to know how this could have happened. How could her son suddenly run out of insurance?

But it had happened. Michael had used \$1 million in insurance, capping out. He was no longer insured.

Michael had been enrolled in Alan's insurance since birth. Alan is an electrician with the IBEW International Brotherhood of Electrical Workers, which has its own insurance. Although eligible for her own insurance policy through the city of New York as a teacher, Kaaren elected not to enroll, to save money; instead, she took a waiver that allotted her \$1,000 a year. Every year, the Zielinskis renewed Alan's insurance, and signed a waiver with Kaaren's insurance policy.

Every year since enrolling Michael in 1991, the Zielinskis received and reviewed the insurance policy book. Every year, it stayed the same. Or so they thought. In 2004, unknown to the Zielinskis, the policy changed — there was now a cap. Michael had used an average of 460,000 IU annually since 2004. He had exceeded the \$1 million cap three times, until the insurance



Kaaren Zielinski and son Michael

company caught it in 2008. Michael's insurance was terminated.

“They should have stamped *urgent* on the letter accompanying the 2004 policy book, or on the envelope,” says Kaaren bitterly, “to alert us of the change in policy. Of course, I would have enrolled in my teacher's insurance had I known; then we could have had a backup insurance. But there was no time. Just when you think life is good, you get hit between the eyes. I felt frustrated, devastated. But I immediately jumped into action by calling people.”

Kaaren spoke to her HTC social worker, who warned her that she might need a private insurance policy. “But this would be like a second mortgage,” lamented Kaaren. She spoke to another mother of a child with hemophilia, who referred her to NHF's HANDI.\* Kaaren called the manufacturer of her son's product, and the company agreed to donate factor to Michael. She called the New York City Board of Education to beg for her secondary insurance. She was told that being without insurance was not

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### Kaaren's advice for parents of children under age 18

- ✓ Stay calm! Help is available. Speak with your HTC social worker first.
- ✓ Don't divulge too much about your child while you ask questions of your insurer. Don't mention hemophilia; just say he'll be without coverage. The insurer will probably be more concerned about a transfer period and their policies than about his disorder.
- ✓ Check out the manufacturers' free factor programs. Enroll now if coupons are used. It's a great relief to know these companies have factor to donate.
- ✓ Read your insurance policy at all times, every time. We all receive it, but often don't read it. Look for policy changes that could hurt you, like the institution of a cap.
- ✓ Monitor your caps. Call your insurance company today to find out how much of your cap you've used.

\* Contact HANDI at 800-42-HANDI or [handi@hemophilia.org](mailto:handi@hemophilia.org)



# Q What will the hemophilia industry look like in five years?

interviews by Sara P. Evangelos



**Glenn Mones**

Vice President for  
Public Policy,  
National Hemophilia  
Foundation

We've seen a number of trends in the last few years

regarding access to healthcare, access to factor, and reimbursement. One trend is a reduction in the number of providers of clotting factor through consolidation of specialty pharmacies. We've also seen sole-source or limited-source contracts between large insurers and select factor providers, where large private insurers or state insurance programs have moved from working with many providers to one, two, or three providers. That's a reflection of payers' desire to reduce costs and simplify their business. This trend is likely to continue.

There is a move toward reducing reimbursement formulas across the board. We've seen that in Medicaid. We've seen it in private insurance, through tier 4 pricing, which could be applied to factor in the future. We've seen some efforts, mostly unsuccessful, to limit access to the full range of products by putting factor on preferred

drug lists for Medicaid or on restricted formularies for private insurance.

These efforts are likely to continue, but whether they succeed will largely depend on whether research produces data about the unique qualities of the different products. Payers are asking hard questions: Why is one factor concentrate brand different from another? Why do you need access to all products? If we don't have the hard data to clearly indicate why access to the full range is necessary, then it's possible — even likely — that we will see further restrictions: some payers simply won't reimburse for some products, or will set higher hurdles to have access to those products.

This will also affect development of new products, including longer-acting factor products. For these products to come to market, we need reassurance that they're going to be reimbursed.

The bottom line: We need hard data. Access to care and reimbursement ultimately depends on our ability to demonstrate, using good data, that these are things our community *needs*.

I think we'll see some additional options for coverage come out of healthcare reform. There will likely be some better options offered by private insurers as a result of this process, as well as a possible government-sponsored public plan. The question is, will

those options be adequate for the needs of this community? We all need to send the message that there must be plans that adequately reimburse for things this community needs, that do not restrict access to products, and that do not place inadequate caps on benefits.



**Michelle Rice**

Regional Director for  
Chapter Services,  
National Hemophilia  
Foundation

We will definitely see reimbursement being much

tighter. I think we'll see less profits for factor. I still believe that people will have choice of factor products. But I think they're going to have fewer choices of where they can get it. I think that many insurers and Medicaid offices understand the differences between the different factor products, and will start trying to understand utilization a little better. We'll have to watch very closely that they don't limit how *much* we can have. That's a bigger concern than their forcing us down to one or two products. I think most people will have more limited networks. States with "any willing provider" laws will set a

flat rate and say, “This is the most we’re going to pay; anybody who can do it can be a provider.”

Medicaid is trying to save money, so I think we’ll see more interest in standards of care and standards of service. Hopefully that will spill over to private insurers. The most important thing will be for patients to pay attention, to be responsible with their healthcare dollars, to make sure that they aren’t over-stocking — all those things paint a target on us — and to make sure they understand what they’re paying, and know the rules and limits of their insurance company or Medicaid provider.

Regarding the future of hemophilia healthcare, I think that people with hemophilia need to be worried about access, not so much choice: *access* to care and access to products. And they need to be concerned about the *adequacy* of their care, and the adequacy of their insurance. Because just having access to health insurance does not necessarily mean that it will cover what you need it to cover.

It’s important for people to be proactive rather than reactive; I think that’s one reason that here in Indiana, we’ve been successful. Because we knew eventually they were going to make changes, we went in and said, “We want to help make changes.” And I know that the other state Medicaid programs are looking at making changes now.



### Craig Mears

President, Accredo's  
Hemophilia Health  
Services

As more people face the prospect of job loss, we need to find resources to

catch people before they fall through the cracks. COBRA benefits are expensive, and a person with hemophilia who can’t afford to pay the premium won’t automatically qualify for Medicaid. Some organizations, like Patient Services Inc., pay insurance premiums for patients who qualify; however, their funds are limited. I’m afraid we’ll end up with a lot of people needing help from the support services in the community. Many of the state Medicaid programs are looking at lowering pricing for reimbursement, and at putting preferred provider agreements in place to narrow the number of pharmacy providers they work with.

Commercial insurance companies are also looking for ways to cut costs, in an effort to show employers that they can provide value. National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC) publishes guidelines for standards of service in hemophilia.\* If these guidelines are not implemented in all states, the quality of services patients receive could suffer.

The community needs to come together around common issues like standards of service. By working to get standards of service passed, more

patients can benefit from consistent quality of care.

Standards of service can help the bleeding disorder community with their choices and continue to empower them to *have* choices.



### Joe Pugliese

President, The  
Hemophilia Alliance

The last five years have seen a tremendous consolidation in manufacturing, pharmacy

companies, and third-party payers. We’ve also seen the emergence of the payer/pharmacy provider. Billions of dollars have been spent in each segment of the marketplace on eliminating competition. The strategy has been most successful in those industries with the highest barriers to entry, manufacturing and insurance. It has been far less successful in the pharmacy space.

Consolidation in manufacturing has ensured that we have financially secure suppliers of lifesaving products. New therapies for hemophilia are in the pipeline. The community would benefit from either more manufacturers or more competition based on price. Yet the industry is looking to consolidate even further.

It’s hard to see where consolidation in the insurance industry has helped the community. There is a growing inability to access health insurance, even with higher co-pays and premiums.

*continued on page 15*

\* Standards of Service (or care) are guidelines that hemophilia distributors (SPPs and HCCs) are required to follow if this legislation is passed in a state. It includes requirements for open access to all therapies, pharmacy guidelines, and hours of operation. For the text of the guidelines, see NHF’s Medical and Scientific Advisory Council (MASAC) at [www.hemophilia.org](http://www.hemophilia.org)

### Mature Years

We're fortunate that today, many people with hemophilia live to age 64 and beyond. Safer products and comprehensive care available at HTC's contribute to longer lives. In this stage, you are preparing for retirement, which may mean loss of insurance coverage or reduced benefits. You may face more medical treatments, either related to hemophilia, like joint replacement, or related to age and lifestyle, like diabetes or cancer.

Many members of our community, already in their mature years, face payments for coinfections such as HIV and hepatitis C. Some never expected to live this long and didn't have the luxury or hope to prepare. The younger generation will have no excuses: information abounds on how to prepare for this stage of life.

Fortunately, medical insurance is available for all. Medicare is an entitlement program that the government provides to all citizens. It's the nation's largest health insurance program,

insuring 40 million people, age 65 and older, or with various disabilities. This is essential because it's difficult to get regular health insurance after a certain age. Older people are considered at risk of increased health concerns. As you probably know, the goal of health insurance is not necessarily to help the sick! So even if you have insurance benefits through retirement, you will eventually have Medicare.

#### What you need to know:

- You are eligible for Medicare when you turn 65.
- Medicare includes four parts: A, B, C and D
- Factor is covered under both Parts A and B.
- Part A covers hospital insurance and is free.
- Part B covers factor concentrate and costs \$96.40 per month, covering 80% of costs. Know what a supplemental policy is.
- You may not need Part B if your retirement benefits include factor.
- Enrollment in each part is time sensitive, so don't miss deadlines.
- Depending on your coverage, factor could still require a hefty co-pay.

#### What you need to do:

- Register with your manufacturer's patient assistance program.
- Sign up for Medicare three months before turning 65.
- Consider getting a Medigap<sup>6</sup> policy to supplement Medicare.
- Review your insurance retirement benefits before retiring. Know what your employer will and will not cover.

Insurance for patients with hemophilia is often cited as the number-one challenge of hemophilia — even more than bleeds. Help is available for almost everyone in our national community, yet frantic calls are still made by people who have lost or are about to lose their insurance.

The truth is that for people with chronic disorders like hemophilia, maintaining insurance requires constant vigilance at each stage of life, and within each stage. You will always be your best advocate. Keep the lifeline of insurance always within reach by preparing before you reach the next critical stage of life. —

6. Medigap is supplemental insurance provided by private insurance companies to cover certain gaps in coverage in Medicaid.

### Transitions *from page 3*

for the program before your insurance expires. Be sure to research your factor manufacturer's programs *now*.

### Your New Policy

When you consider a new policy, review the policy closely, and ask these crucial questions:

- Is my factor covered?
- Are there brand restrictions?
- Is there a lifetime maximum?
- Is there a pre-existing condition clause?

Many families worry that a new insurance carrier will deny coverage based on pre-existing condition clauses. The Health Insurance Portability and Accountability Act (HIPAA) provides protection against these clauses when you change jobs or insurance plans. Under HIPAA, if you are eligible for a group health plan, you can't be denied coverage — or have your coverage canceled — for a pre-existing condition if

- you've had at least 12 months of continuous coverage, and
- you've had no lapse in your coverage for 63 days.

Maintaining insurance coverage is a vital part of managing your hemophilia. In these uncertain economic times, you can alleviate some stress by reviewing your policy, planning for contingencies, and developing a strategy to help you maintain continuity of care. —



### Community Forum from page 13

The pharmacy/insurance industry seems hard at work erecting barriers to entry. New expensive therapies, across a wide array of disease states, are being brought to market through limited or exclusive distribution channels. Limited distribution tends to drive up prices.

One payer is trying to auction off its pharmacy network to the highest bidder. The market values the deal at between \$1 and \$5 billion. The differential seems to be based on some preferential access to the insurer's covered lives.

Consolidation is making it increasingly difficult for smaller commercial and HTC-based pharmacy providers to stay in-network. It seems certain there will be fewer factor providers in five years.

The Hemophilia Alliance is committed to keeping HTCs competitive and able to continue the excellent clinical care they have provided for years. We are committed to NHF MASAC 188 standards. We are reaching out to third-party payers to make sure they understand all of the benefits of having their patients seen at a federally funded center. HTCs have never been for sale, have been here since 1975, and plan to be here five, ten and twenty years from now. —



### Real Life from page 11

a qualifying event — but divorce was!

A breakthrough came when Kaaren called Mayor Bloomberg's office. The office agreed that her son's situation was a qualifying event, and eventually, after much paperwork, Kaaren's application for insurance through the city was approved, and Michael was enrolled.

The painful process gave the Zielinskis a powerful lesson in how to be advocates for their son's coverage. And even more valuable, Michael saw his parents in action. He now knows what it takes to watch over his own insurance some day. —

### Ask the Expert from page 10

How much you pay out of pocket for that co-payment depends on how your insurance company classifies your drug. Under the pharmacy benefit, drug plans traditionally have been designed using *tiers* that group drugs by similar cost-sharing requirements, often a three-tier design with an increasing co-payment for each tier. Tier 1 drugs, usually generic drugs, normally have the lowest co-pays. Tier 2 drugs have a higher co-payment and are "preferred" brand-name drugs (often advertised on television). Tier 3 drugs are assigned the highest co-payment. These are "non-preferred" brand-name drugs, more expensive drugs, or drugs lacking proof of greater effectiveness. Some health plans have added a fourth tier for specialty or biologically derived drugs, such as factor.

Some health insurers have created a special pricing category for specialty drugs. On a fourth tier, consumers are charged either an increased co-payment or a percentage of the actual cost of the drug. Fourth tiers can require you to pay 25% to 35% of the drug price.\*

Currently, factor is typically covered under the medical benefit and will not be impacted by this new tier 4 category. But increasingly, private insurance plans are shifting factor to the pharmacy benefit or creating a new specialty drug benefit that uses tiered co-payments.

It's essential to monitor *where* in your health insurance factor is covered. Your insurance company may change this benefit at any time and should inform you of any planned changes. —

**As Vice President of Healthcare Economics and Reimbursement for Baxter BioScience, Mike Bradley has responsibility for division-wide reimbursement, government policy, and health economic strategies for all Baxter BioScience products. He has an MBA in marketing management, and worked in a clinical laboratory for more than thirteen years before joining Baxter. The Department of Healthcare Economics and Reimbursement specializes in healthcare advocacy and reimbursement support for consumers, providers, and medical professionals.**

\* Walsh, Bill. "The Tier 4 Phenomenon: Shifting the High Cost of Drugs to Consumers." *AARP Intelligence and Briefing Report*. March 2009. [www.aarp.org/research/health/drugs/tierfour](http://www.aarp.org/research/health/drugs/tierfour)

## Introducing

### CARE (Coverage, Assistance, Resources, Education) Program

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

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

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