

PEN's Insurance Pulse

Inspiring Advocacy

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Could Cost Controls Prevent Access to Your Factor Brand?

Wendy Owens

Do you believe in predictions?

In 2005 PEN predicted, "Drastic cost cutting by those who pay for our factor could cause some surprising changes in your choice of factor brand, and in the way you receive and use it."¹ Since then, the insurance industry has visibly exerted more and more control over your choice of factor provider; this may have affected you when your specialty pharmacy was suddenly switched without your consent. Now be prepared for payers to limit your ability to choose any factor brand. Their stated reason? Cost control.

Cost control is reasonable if the methods used don't limit access to your preferred brand of factor. Yet the controls put in place over the years may make it harder for patients like you to get the factor brand you want and need. You, your hematologist, and your factor provider may all find it increasingly harder to control which factor brand you receive. As you'll see, cost controls can make it more expensive and more difficult for you to obtain your preferred brand.

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1. Lauren A. Kelley, "The Coming Storm," *Parent Empowerment Newsletter* 15 (1).

Welcome

PEN'S INSURANCE PULSE

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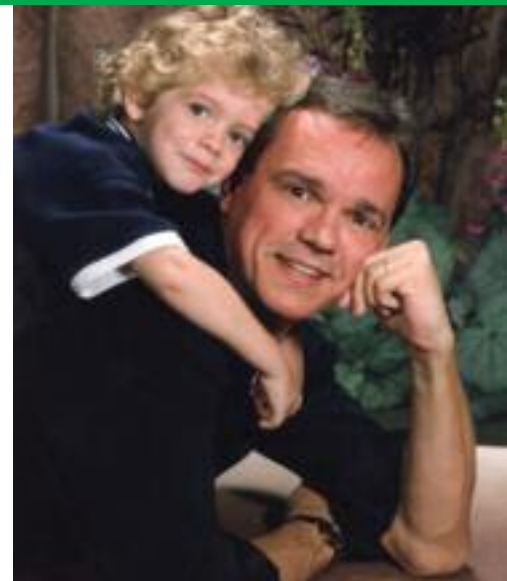
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I have been called a few things in my life—passionate, proactive, athletic, risk-taker, goofy (by my kids), professional. Never a good cook. Recently, I've been called alarmist. Why? Because I've pointed out changes in insurance that are happening around the country, to warn our community about trends that threaten our access to therapies we need. Sometimes, in this age of social media, you need to speak with fire to get folks' attention. And sometimes you need to go out on a limb to predict what might happen to us as patients.

I did this 10 years ago when I published my article "The Coming Storm" in PEN. I warned about reimbursement changes afoot, about little-known entities called PBMs, and I predicted that our choice of factor providers (home care companies in particular) would be limited or dictated by insurance companies. People were shocked—especially the home care companies. How dare I predict this? What did I know about the specialty pharmacy business or reimbursement?

It wasn't all me. I was warned about changes to reimbursement by a dear colleague and brilliant mentor, Dave Madeiros, who had hemophilia and HIV and operated a specialty pharmacy. Dave, who passed away in 2004, was visionary—he foretold that reimbursement was permanently changing, that limitations in choice of providers and therapies would happen, and he urged me to publish it. I was skeptical at first, but after months of meetings and brainstorming, I saw the coming storm too. It came,



Dave Madeiros and son, 2003

it went, and we are now dealing with the aftermath.

Now, we are way past restrictions on factor providers. We have more important concerns: payers are starting to restrict our access to brand of factor in certain parts of the country. Maybe even the factor your child is on, and needs. We predicted this, too, 10 years ago. Read Wendy Owens's article about why restriction of brands is happening. Then get in touch with your local hemophilia organizations, and reach out to HFA and NHF to see what you can do to preserve our access to therapies.

Change is inevitable, and we will need to adapt. In fact, we have already adapted. But now, how will we keep therapies available—as many as possible? Our future success will require us to communicate our struggles and stories with the advocacy organizations that are here to serve us, just as Dave communicated what he knew so many years ago.

Laurie



Aging Gracefully:

How to Access Skilled Nursing Facilities

Marla Feinstein

Navigating insurance issues while you're aging is a new field, particularly for our community. The good news is that bleeding disorder patients are aging—living longer—

and can access more treatment options, including surgery. And they face the medical issues typically associated with aging, but sooner than people without a chronic condition. Complications from hemophilia can increase the likelihood of patients needing surgery for damaged joints or liver ailments. To help facilitate recovery while ensuring that their bleeding disorder and complications are adequately managed following surgery, a treating physician may recommend that some patients be placed in a *skilled nursing facility* (SNF) immediately after being discharged from the hospital.

SNFs are ideal for patients because they provide short-term, intensive, inpatient rehabilitative services. And SNFs also have the medical and nursing expertise to provide a level of care far beyond what's available to patients who are treated at home. These services are often critical for optimal recovery.

Unfortunately, it has become increasingly difficult for some patients with bleeding disorders to get admitted into SNFs. The reasons for denial vary. Some SNFs have concerns about the type of specialized care that bleeding disorder patients require. Not surprisingly, the primary reason that SNFs deny access is the cost of and reimbursement for factor concentrates. This difficulty exists regardless of the type of insurance coverage (Medicaid, Medicare, or private) and doesn't appear to be related to any other conditions patients may have, such as HIV or hepatitis C.

How to Pay for Skilled Nursing Facilities?

Understanding exactly how insurers reimburse for factor concentrates administered in SNFs is difficult. This is partly due to the limited number of patients needing the level of care

provided at an SNF. It's also partly due to lack of public information regarding how SNFs are reimbursed by private payers, while state-to-state variability makes it hard to understand Medicaid.

In contrast, Medicare provides very specific guidelines for how SNFs will be reimbursed for factor for all beneficiaries. In general, Medicare pays for different types of care and services under Parts A, B, C, and D. The type of facility, and whether services are provided as inpatient or outpatient, defines how Medicare covers all patients.

Generally, Medicare bundles reimbursement for all the services provided to a patient that are associated with an SNF stay, including nursing, therapy, drugs, supplies, equipment, room and board, and administration. This bundled, lump-sum payment is expected to cover all of the daily operating costs for running and staffing a post-acute care facility such as an SNF, but it doesn't even come close to covering the high cost of factor concentrate (often exceeding \$10,000 a day) for bleeding disorder patients during an SNF stay. Without receiving adequate reimbursement, the SNF will not be able to accept bleeding disorder patients.

Proposing a Partial Solution

It may be challenging for a patient to gain access to an SNF when there are limited or conflicting guidelines regarding how SNFs should bill for services. Though reimbursement for SNFs can be complex when working with any payer, for Medicare, at least, there is a legislative fix.

The Medicare SNF statute allows certain costly, highly specialized services that SNFs do not typically provide to be billed separately under Medicare Part B.¹ Services that can be billed separately include chemotherapy, radioisotopes, certain types of prosthetics, and erythropoietin for dialysis patients. National Hemophilia Foundation (NHF) seeks to add factor concentrate to the list of services that can be billed separately

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1. Centers for Medicare & Medicaid Services (CMS) Consolidated Billing Background: <http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/SNFPSP/ConsolidatedBilling.html>. CMS Overview on Skilled Nursing Facility (SNF) Consolidated Billing (CB): <http://www.cms.gov/Medicare/Billing/SNFCConsolidatedBilling/Index.html>.

What are these cost-control methods? How much more will they cost you out-of-pocket? Let's begin with some background information on healthcare trends, costs, and value. Once you have the big picture, you'll see specific barriers you may face, such as *value-based pricing*, *specialty tiering*, *prior authorization*, and *step therapy*.

Healthcare and Hemophilia by the Numbers

With healthcare costs reaching \$2.9 trillion in 2013,² about \$9,255 per person annually, controlling healthcare costs has become paramount in the US. Healthcare is now the largest economic sector in the country. The Centers for Medicare and Medicaid Services forecasts the cost of US healthcare to grow to an astounding \$5 trillion by 2022.³ What's all this money being spent on?

Of the \$2.9 trillion in healthcare costs in 2013, medication accounted for \$271.1 billion;⁴ only hospital care and physician clinical services had higher price tags. Bleeding disorder therapeutic products—mostly factor—generated \$4.63 billion in revenue in the US last year, and revenues are projected to reach \$6.3 billion by 2019.⁵ But projected increases in revenue aren't based on a forecasted higher number of customers. The US Centers for Disease Control (CDC) estimates the number of people with hemophilia in the US at 20,000; that's only 3,000 more than in 1994.⁶ Projected higher revenues are based on projected higher demand. Increased weights of US patients, longer lifespans, more sports participation, and greater adherence to prophylaxis have led to increased factor use and subsequent higher revenues from factor products.

More Choices, Less Choice

Because treatment of bleeding disorders is a big and growing business, more manufacturers want to get in on the action. You may have noticed some new corporate names providing factor. More factor products than ever before are in the drug pipeline, moving toward potential approval by the US Food and Drug Administration (FDA). Last year was a boon: three new recombinant products received FDA approval, and pharmaceutical companies submitted applications for the approval of other new products. In the US alone, it's projected that seven new factor products will be available in the next two years.⁷ These new products include extended half-life factor, which means fewer infusions per month.

Ironically, even though you have *more* factor choices today than ever before, insurers may control costs by *narrowing* your access to the growing list of options. How does limiting the number of factor products available to you reduce insurers' costs? Insurers control the cost of medications using two main tactics: (1) price negotiations with factor suppliers, and (2) cost sharing with patients through deductibles, copay levels, and coinsurance rates that they negotiate with public and private employers. We'll get to the

second tactic later, but let's begin by examining price negotiation.

An insurer can negotiate lower per-unit prices with a drug manufacturer by promising to reimburse larger volumes of a specific drug; that means dealing or contracting with one or two manufacturers for just a few brands of drugs. Here's the rub: price negotiations that result in cost savings for insurers (and your employer) may mean that your choice of factor brand is not up to you or your doctor, it's up to your insurer. An insurer may negotiate a price based on buying one or two brands of factor in bulk, and these are the only one or two brands available to factor users. Period. And an insurer won't negotiate to purchase just any factor brand—no, it wants brands with the best value.

Value is now a critical element in drug price negotiations; it also affects the second cost-control tactic, cost sharing. Let's continue to connect the cost-control dots by looking at the role that value plays in the competition for healthcare dollars.

2. Robert Peardeck, "Health Spending Rises Only Modestly," *New York Times*, Dec. 3, 2014. 3. National Health Expenditure Projections 2012–2022, Centers for Medicare and Medicaid Services. 4. Ibid. 5. The therapeutic products for bleeding disorders include drugs to treat hemophilia A and von Willebrand disease (factor VIII/von Willebrand factor), hemophilia B (factor IX), inhibitors (factor VIIa), and other doctor-diagnosed bleeding disorders. 6. Centers for Disease Control and Prevention, Statistical Data in the United States for Hemophilia. <http://www.cdc.gov/ncbddd/hemophilia/data.html> (accessed May 28, 2015). 7. *Global Haemophilia Therapeutics Market: Increased Use of Recombinant and Prophylaxis Therapies Drives Growth*, MAD9-52, Frost & Sullivan, April 2015.



Baxalta

THE COUNTDOWN HAS BEGUN.

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[Antihemophilic Factor
(Recombinant), Pegylated]

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Watch Out for Value: It Has a Price

More factor products on the US market means more competition among manufacturers. This increase in competition—coupled with the expiration of long-term patent protection for some current factor products—should drive down the cost of factor, right? Not really. Though the number of people with hemophilia is not increasing much (300–400 babies are born with hemophilia annually in the US), the market value of factor products is rising. Market value is the price at which a seller is willing to sell a product and the price at which a buyer is willing to purchase that product.

The market value of factor is rising because people are using more of it: higher demand for a product can mean a higher price tag. This may be true for new factor products whose value is based on offering a tangible improvement, such as an extended half-life that results in fewer infusions. Market value of factor will start to affect the price of new factor products—possibly your choice of factor—as pharmaceutical companies begin adopting the new value-based pricing model.

Today's Healthcare Model: Value-Based Pricing

About 10 years ago, the Institute of Medicine (IOM) designated *patient-centeredness* as one of six goals for 21st-century healthcare.⁸ This goal of putting the patient first is a cornerstone of the Affordable Care Act (ACA) of 2010. The ACA requires that patients come first, and that they receive valuable services for their premium and out-of-pocket dollars. The requirement that healthcare providers deliver valuable care to patients has led to a dramatic shift in healthcare delivery models. The old model was a cost-based reimbursement model: providers were simply paid for the services they provided at a set price. The more services they provided, the more money they made.

Today's model is value-based. Value-based reimbursement is built on a three-legged stool: (1) patient satisfaction, (2) cost, and (3) health outcomes. Providers must succeed at all three to compete for reimbursement dollars. In other words, the more bang an insurer can get for its buck, the more value the healthcare provider has delivered, and the more the provider should be rewarded for this value.

Value-based pricing has been adopted by the pharmaceutical industry in its model for biologic drugs like factor. Now pharmaceutical companies are calculating the amount they charge for a drug based on its value—its worth to the consumers who want it. For example, in December 2013, Gilead Science began selling the drug Sovaldi, which cures hepatitis C in more than 90% of patients. In the US, Sovaldi cost \$84,000 for a 12-week regimen—about \$1,000 a pill. The \$84,000 represented the value of the drug to the patient, not what the drug cost to manufacture.

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8. Michael L. Millenson and Juliana Macri, *Will the Affordable Care Act Move Patient-Centeredness to Center Stage? Timely Analysis of Immediate Health Policy Issues*, Robert Wood Johnson Foundation, Mar. 2012.

Tracks & Trends

Test your **knowledge** of insurance **facts** and **figures**!



Buyer's market

1 **Nine manufacturers are now licensed to sell factor in the US. What are the correct, official names of all nine?**

- a. Bayer, Baxter, Biogen, CSL Behring, Emergent BioSolutions, Grifols, Novo Nordisk, Octapharma, Pfizer
- b. Bayer, Baxter, Biogen, CSL Behring, Grifols, Novo Nordisk, Octapharma, Pfizer, Talecris
- c. Bayer, Baxalta, Biogen, CSL Behring, Emergent BioSolutions, Grifols, Novo Nordisk, Octapharma, Pfizer
- d. American Red Cross, Bayer, Baxalta, Biogen, CSL Behring, Grifols, Novo Nordisk, Octapharma, Pfizer

Is the ACA Health Insurance Marketplace working?

2 **As of March 31, 2015,**

- a. most Americans were boycotting the Marketplace.
- b. about 10 million Americans had purchased coverage through the Marketplace.
- c. about 1 million Americans had purchased coverage through the Marketplace.
- d. about 10 million complaints were filed with the government about the Marketplace.

Medicaid expansion

3 **The ACA provides for a Medicaid expansion, allowing more people to join Medicaid, by changing the definition of who is eligible. From October 2013 through March 2015,**

- a. over 5 million additional individuals enrolled in Medicaid and CHIP.
- b. over 20 million additional individuals enrolled in Medicaid and CHIP.
- c. over 12.2 million additional individuals enrolled in Medicaid and CHIP.
- d. Medicaid had to turn people away because its budget went bankrupt.

Got insurance?

4 **Since the passage of the ACA five years ago, about 16.4 million uninsured people have gained health coverage. Those gains come mainly from**

- a. the Marketplace.
- b. young adults who can stay on their parents' plans until they turn 26.
- c. Medicaid expansions.
- d. all of the above.





Ask the Expert

Elizabeth Stoltz
Baxalta Director of US Patient Advocacy, Hemophilia

Q: The rules seem to keep changing even though I've had the same insurance plan for several years. How do I make sure I don't get any unpleasant surprises in January?

A: First and foremost, *read the material* you get during open enrollment. If you have insurance through your job, the human resources department will typically send information once a year, about a month or so before you can sign up. Or go to your insurance company's website and read your plan's information online. You may have a choice of plans. Even if there's only one choice, you still need to understand plan changes from one year to the next.

Sometimes the materials will specifically note what's changed from last year, but I recommend confirming some additional things:

- Is your factor covered the same way it was last year? For example, if your factor has typically been covered under the medical benefit, is it still covered there, or has it been changed to a pharmacy benefit?
- If your factor has changed from medical to pharmacy benefit, for example, has your copay changed? If your

factor is now covered under the pharmacy benefit, you might have a coinsurance instead.

- Is your brand of factor available on your plan?
- Has your factor provider changed? This includes home care company, specialty pharmacy, or 340B pharmacy at your HTC.
- Is your HTC in-network?
- Have any copays or coinsurances changed for HTC visits, emergency room visits, or any service you think you might need in your new plan year?

The NHF Personal Health Insurance Toolkit¹ has a list of questions for evaluating and comparing plan choices. The toolkit is also helpful for looking at your next plan year's documents to see if anything has changed.



Q: I used the NHF Toolkit, and I did see some changes for my next plan year. My deductible is higher and my coinsurance for factor is higher too. What should I do now?

A: Because you're aware of the extra up-front cost, consider saving some money for the deductible. Start saving for that extra expense at the beginning of your plan year.

Check to see if your factor's manufacturer offers a copay/coinsurance program. Many do. NHF has a list of these programs on its website: <http://www.hemophilia.org/Advocacy-Healthcare-Coverage/Key-Advocacy-Issues-and-Materials/Fact-Sheets/NHF-Summary-Of-Patient-Assistance-Programs>. HFA also has a list: <http://www.hemophiliamed.org/resource-library/navigating-patientassistance-programs>.

Coinsurance: Your share of the costs of a covered healthcare service, calculated as a percent (for example, 20%) of the allowed amount for the service.²

Copay: A fixed amount (for example, \$15) you pay for a covered healthcare service, usually when you get the service.³

Deductible: The amount you owe for covered healthcare services before your health insurance or plan begins to pay. For example, if your deductible is \$1,000, your plan won't pay anything until you've met your \$1,000 deductible for covered healthcare services subject to the deductible.⁴

Elizabeth Stoltz has worked in the healthcare industry over 20 years and has been tracking healthcare reform since 2010. She has educated patient organizations, individuals, HTCs, and specialty pharmacies on healthcare insurance. She is an active volunteer with Arizona Adopt A Greyhound and serves on the board of directors for a local healthcare agency in Phoenix, Arizona.

1. Toolkit: <http://www.hemophilia.org/Documents/Personal-Health-Insurance-Toolkit>, 7. 2. <https://www.healthcare.gov/glossary/co-insurance/> (accessed May 29, 2015).

3. <https://www.healthcare.gov/glossary/co-payment/> (accessed May 29, 2015). 4. <https://www.healthcare.gov/glossary/deductible/> (accessed May 29, 2015).

When Goliath Insured David:

How to Get What You Need When the Giant Doesn't Listen

Patrick James Lynch

Anyone with a bleeding disorder knows that navigating the healthcare system can be extremely difficult, and sometimes a downright nightmare. Unfortunately, our community's size—or lack thereof—puts us in a vulnerable position; there simply isn't enough education or understanding about our needs, and this happens on the medical side (hematologists and nurses) as well as on the business side (insurance and reimbursement specialists).

I have severe hemophilia A. In early 2014 I needed a new insurance plan. I'd moved from New York to California. I didn't know much about the healthcare culture in California, so I contacted a navigator—a person trained to assist people seeking health coverage through the Affordable Care Act's Marketplace. I knew she'd worked in hemophilia, and thought her expertise would help me select a plan. She pointed me toward a plan with Sanitas Healthcare*, and I enrolled.



Patrick James Lynch



Sanitas Healthcare works differently than most health insurance companies. For one, it's not just a health insurance company; it's an integrated delivery system (IDS), a network of healthcare organizations operating under one umbrella. The IDS model is one example of a managed care system that's grown more popular in recent years as a means of making healthcare coverage cost-effective for the insurance provider. Sanitas is not only a health insurance provider, but the company owns the hospitals its patients must visit under their plans, employs the doctors its patients can see, and controls the pharmacies where its patients receive medication. In lay terms, Sanitas controls everything. It's gigantic, with over 9 million patients across eight states plus Washington, DC. Sanitas has over 174,000 employees, and in 2013, it reported \$53.1 billion in revenue. Yup, *billion*. Sanitas is the largest managed care organization in the United States.

Enrolling with Sanitas I felt safe. Unfortunately, Sanitas turned out to be a terrible selection for someone with hemophilia, especially an adult patient—something my navigator friend was not aware of because she'd worked in pediatrics.

Member Services: How Can I Not Help You?

The first problem emerged immediately with the wrong information from Member Services. I was told I was unable to schedule an appointment for the first five weeks following registration. This included not being able to order factor until a Sanitas doctor wrote me a new prescription. Multiple customer services agents confirmed that there was no way around this protocol. Yet I found out later from a Sanitas executive that what I'd been told directly contradicted company policy: new

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** The company name has been changed for anonymity.*

Community Forum

Q How has the Affordable Care Act affected people with rare bleeding disorders or complications?

Community forum members represent unique perspectives and areas of expertise in the bleeding disorder community. Here, three participants describe their experiences with insurance under the Affordable Care Act (ACA). Michelle Rice, vice president, Public Policy & Stakeholder Relations of National Hemophilia Foundation, offers advice after each person's story.



Natasha Thompson and husband John
with son Caleb, age 6, Texas

Inhibitors

MY HUSBAND AND I HAVE SOMETIMES HAD private insurance, when we could afford it. At other times, Caleb has been on Medicaid and CHIP (Children's Health Insurance Program). At the end of 2013, the Health Insurance Marketplace opened up and we decided to apply for a plan.

My HTC social worker told me how to find a healthcare plan using the Marketplace. She said my plan had to cover blood-clotting products, and explained how to make sure Caleb's hematologist was in-network.

My experience with the state Marketplace website was awful due to various glitches in the system. After several failed attempts to create an account, multiple calls to the Marketplace representative, and long stretches of time on hold, and after *three weeks* of logging in, I was finally able to create an account and *begin* the search for a new plan.

I found an affordable Marketplace plan that listed Caleb's hematologist and covered his factor. Because we didn't qualify for a subsidy, the plan would cost half my salary, with the other half eaten up by daycare costs. But we decided to tough it out, so I chose this plan and had 30 days to pay for it. Then I learned that I had to have signed up before the 15th of the month to receive coverage at the start of the next month. So Caleb would go one month with no health insurance. I filled out forms through our HTC to receive free factor from our factor manufacturer.

February 1, 2014, was supposed to be the first date of coverage on our Marketplace plan. I was thrilled. But by the end of January, I still hadn't received my insurance card. I called the insurance company and spent two hours on hold. Finally, a rep told me the Marketplace would have that information. After 45 minutes on hold, the Marketplace said they didn't have that info and our insurance company would.

So I waited two hours on hold with the insurance company again, finally getting our group number, which I gave to my social worker. Then she informed me that Caleb's hematologist was contracted with the insurance plan, but the HTC was not.

In February, we were dropped from the free factor list. Due to the insurance squabble, we still couldn't receive factor. Patient Services, Inc. (PSI) was able to

reimburse us for our premium cost, and I began paying for the new Marketplace insurance that didn't take our HTC.

Our social worker then explained that only two Marketplace plans were contracted with our HTC, and only one would cover Caleb's factor, but that was not the plan we were currently enrolled in. Many people at our HTC spent hours on the phone for us figuring all of this out.

In the end, I quit work to spend time with Caleb, who was now nearly constantly at the hospital. He got covered via CHIP on April 1. I spent several hours on the phone (mostly on hold) and online with the insurance company and Marketplace trying to cancel my plan, which I finally did on April 12.

Michelle's Take

The initial enrollment period for the Marketplace was October 1, 2013 to March 31, 2014. It's true that the inaugural Marketplace website experienced multiple glitches. Although certain *essential health benefits* such as specialists and prescription drugs had to be covered by the Marketplace plans, they were not required to cover *all* options. The burden to choose the "right" plan for specific needs fell to consumers, and navigating the health plan websites to identify which providers and medications were covered was often difficult. These obstacles resulted in missed deadlines and delayed coverage for some.

Michelle's Tips

- Review your options thoroughly to ensure your needs are covered.
- Never assume. If you're unsure about a benefit, contact the health plan directly and ask for clarification, preferably in writing.
- Ask for help. Your HTC social worker is an excellent resource.
- Document your conversations related to your healthcare coverage: date, time, name of person you spoke to, what you asked, and the answer you received.



Kelly Gonzales (r) with daughter Jacey, Nevada

von Willebrand Disease (VWD)

MY DAUGHTER JACEY AND I BOTH HAVE VWD, but hers is much more severe. She suffers from joint bleeds, muscle bleeds, multiple breakthrough bleeds, and multiple menses per month.

We had two insurance options: a private health trust with several different plan options, and a private insurance plan. Due to lack of time, we chose a health maintenance organization (HMO) because the premium increase was lower. I researched the plan and discovered that all our doctors, including our hematologist, were covered.

After our first visit with our hematologist under our new HMO plan, our specialty pharmacy told us the insurance wouldn't approve Jacey's factor. I called the insurance and was told the HMO hematologist should not have been approved, and they would not cover the factor. I appealed, and lost.

Jacey saw her pediatrician of 13 years, who then wrote her factor prescription. Insurance denied it, claiming the doctor wasn't authorized because hematology wasn't his specialty. Our insurance company said that because Jacey was now 16, she had to see an adult hematologist, covered by the plan. We called him and were told that the office does not accept pediatric patients!

We now had no access to an approved hematologist and no access to clotting factor.

Jacey was hospitalized with repeated fainting, and joint and muscle bleeds. Eventually, the insurance company got us an appointment with the hematologist contracted with the plan (the same one who'd previously denied us), who refused to continue Jacey on the treatment plan she had been successfully following for years. Instead, Jacey was forced to undergo bloodwork and return to treatment therapies that had proved ineffective for her.

Only one call was returned in the 18 we made to this doctor's office, and not by a medical professional, but by the office manager, who apologized that we were getting such bad treatment.

Eleven hospitalizations and multiple appeals later, we finally got a meeting with 13 insurance executives, including medical directors—thanks to a push from NHF and Michelle Rice. We presented an 18-page document listing every call, every contact name, and the results. We presented our EOB and proved that the cost of going to the HTC

would be significantly less than the cost of her pediatrician. We provided solid proof that seeing the HTC doctor and being on prophylactic treatment would be financially beneficial to the insurance company, as well as physically and mentally beneficial to the patient.

The insurance company gave us exactly what we wanted: approving the HTC doctor and prophylaxis for Jacey. They agreed to full coverage for her throughout college. And they assigned us a caseworker to be our point of contact. Jacey decided that it wasn't enough: she wanted the insurance company to guarantee that no one else had the same experience.

She gave the insurance company an eloquent speech, concluding, "You can't give me back my youth, you can't give me back the two years I lost...I'm asking for you to be sure that this doesn't happen to anyone else." There wasn't a dry eye in the room. Since that meeting, we've returned twice more to talk with department heads and medical directors as well as representatives from the parent insurance company.

A month later, the company sent a rep to meet with us at NHF, and I invited community members, HTC CEOs, and HTC doctors. We discussed needs: specialty pharmacy options; the ability to go to the ER for bleeding issues without prior authorization; not having to jump through hoops for referrals for bleeding-related issues. Although not all our concerns were met, some were. We continue to advocate for the needs of people with bleeding disorders in our state.

Michelle's Take

This is a testament to the importance of documenting your actions and being persistent. Believe it or not, insurance providers want to make sure you receive the appropriate coverage to remain

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Cost Controls *from page 5*

Insurers have balked at high prices of biologic drugs such as Sovaldi. Recently, Express Scripts Holding Co., a prescription-drug benefits manager for US employers and insurers, was negotiating drug prices with pharmaceutical companies. It advised the companies that it would “set pricing for some cancer drugs based on how well they work.”⁹ This is a pushback by insurers who want to pay only the value that a drug provides each individual patient. Value-based pricing might not affect factor products until a product helps to make huge quality-of-life improvements, such as reducing infusions to one every six months, but it’s something leaders in the bleeding disorder community are watching as a potential barrier to product access.

Is value-based pricing fair? “Pharmaceutical companies have a right to recoup the cost of research and development for a successful drug, and even for those not successfully developed,” says Dana Kuhn, president of Patient Services, Inc. (PSI). “Value-based pricing would become absurd if the same companies make it cost-prohibitive for a person with a chronic disease to afford the drug. It makes sense that pharmaceutical companies charge more for valuable drugs, but they should not make the cost so high that the people the drugs are intended to treat cannot afford them.”



Dana Kuhn

Your Need to Manage Insurance Costs

If value-based pricing leads to higher factor prices, you’ll need to carefully

monitor your healthcare expenditures. The ACA may have ushered in healthcare victories for the bleeding disorder community, such as eliminating lifetime caps and prohibiting discrimination against pre-existing medical conditions, but insurers have devised ways to circumvent these victories to control costs. Which brings us to the second tactic used to control costs: cost sharing. This means dipping into your wallet as you share healthcare costs with insurers.

There are some restrictions on how much of the cost insurers can foist on you. To make healthcare and medications more affordable, the ACA set an annual cap on out-of-pocket costs for individuals and families. In 2015, the maximum out-of-pocket costs are \$6,600 for an individual plan and \$13,200 for a family. Some private insurers set their own out-of-pocket limits for their customers even lower than the ACA limit. Nice to know there’s a limit on such costs, but there’s also a catch: insurance companies are starting to change how they calculate out-of-pocket costs. For example, they may not count your deductible toward your total out-of-pocket costs. Don’t ignore this tactic: in the past eight years, the average deductible for individual coverage has more than doubled, from \$584 to \$1,217.¹⁰ If your deductible doesn’t count toward your out-of-pocket limit, your annual out-of-pocket costs could skyrocket.

“Over the last several years we have undoubtedly seen an accelerating trend in high-deductible health plans,” says Eric Hill, chief operating officer at BioRx, a specialty pharmacy. “We are seeing not only an



Eric Hill

increase in the number of patients with high-deductible plans, but also an increase in the size of the deductibles in those plans. Five years ago we saw few \$10,000-deductible plans, and now it is a very common occurrence.”

As if rising deductibles aren’t enough, insurers use other cost-control methods that can make it hard to obtain specific factor brands.



Specialty Tiers

An increasing number of health insurance providers are using specialty tiers to shift the cost of factor onto patients. Even though the ACA has put a limit on annual out-of-pocket costs, specialty tiers can erect a true barrier to factor availability.

The pharmacy benefits side of most health insurance plans uses a traditional three-tier drug formulary (see box, p. 13) that helps determine which drugs are covered at what copay rate. Specialty tiers are a fourth tier for biologics, such as factor, that require a different copay structure.¹¹ Specialty tiers use a coinsurance rate, that is, a cost-sharing percentage ranging from 20% to 33% or more of the cost of a drug, rather than a fixed copay like \$25 per prescription refill. Imagine what your out-of-pocket cost might be if

9. Peter Loftus, “New Push Ties Cost of Drugs to How Well They Work: As Drug Costs Rise, Express Scripts Seeks New Payment Deals for Some Cancer Medications,” *Wall Street Journal*, May 26, 2015. 10. Laura Ungar and Jayne O’Donnell, “Dilemma over Deductibles: Costs Crippling Middle Class,” *USA Today*, Jan. 15, 2015. 11. In 2004, when the Robert Wood Johnson Foundation started tracking the use of a fourth tier (a specialty tier) on drug formularies, it found an 800% increase in the number of plans covering employees using a specialty tier. Sally McCarty and David Cusano, “Specialty Tier Pharmacy Benefit Designs in Commercial Insurance Policies: Issues and Considerations,” Center on Health Insurance Reforms, Georgetown Health Policy Institute, Robert Wood Johnson Foundation Issue Brief, Aug. 2014.

you were required to pay 25% of factor costs without the ACA out-of-pocket limit!

Tiers for Fears?

Tier 1 = generic drugs

**Tier 2 = preferred
brand-name drugs**

**Tier 3 = non-preferred
brand-name drugs**

Specialty tier = biologic drugs

In 2006, a year after the prophetic PEN article, Medicare Part D began using specialty tiers to *lower* drug costs.¹² The reasoning? If patients had to pay a lot out-of-pocket for a brand-name drug when a cheaper generic drug existed, then they'd choose to save money by selecting the generic. The problem is, biologics like factor have no generic equivalent. Following Medicare's lead, private insurers also began using specialty tiers but for the purpose of shifting the cost burden onto the patient.

"While it seems as though specialty tiers should save insurers money, several studies have shown that eliminating the specialty tier and its coinsurance requirements would only cost all people in the insurance pool a couple of extra dollars a year, while keeping the specialty tier intact ultimately drives up costs dramatically for individual patients using biologics," says Caitlyn Donovan, director of outreach and public affairs at the National Patient Advocate Foundation.

"Not only do patients face a larger cost per prescription," explains Donovan, "but patients with larger out-of-pocket costs tend to not fill their prescriptions or not take them properly in order to save money. [Specialty tiers] ultimately worsen their health and drive up sys-

temic costs because of catastrophic care needs." In fact, high out-of-pocket expenses create a significant barrier to care. Studies show that higher copayments can lead to nonadherence—patients stopping their prescribed treatments.¹³ Nonadherence to medication results in \$100 billion spent each year in the US on avoidable hospitalizations.¹⁴

Reimbursement of your factor may currently be under the medical benefits side of your policy. Beware if it's switched to the pharmacy benefits side, where specialty tiers are located. This switch can cause all kinds of problems when you need to order factor. Lori Long learned this when her son's factor coverage was moved to the pharmacy side: "I was told that only 3,000 IU vials would be available through our new pharmacy, and I would be responsible for 20% of the cost of each vial."

Many states, such as New York, Vermont, and Maine, have enacted laws that prevent the use of specialty tiers or limit the out-of-pocket amount an insurer can require a patient to pay for drugs on specialty tiers. Even though the ACA has set out-of-pocket limits at the federal level, these states believe it is necessary to take an additional step to decrease the burden of out-of-pocket costs. The goal of the legislation was to prevent patients from reaching their out-of-pocket limits within the first few months of their insurance plan year when their annual out-of-pocket limit resets.¹⁵ The states found that the majority of people using drugs on specialty tiers could not afford to pay the ACA out-of-pocket limits in the first few months of the year. Specialty tier laws minimize the burden of out-of-pocket medication costs.

At the federal level, Congress recognizes that specialty tiers are a problem. This year, the Patients' Access to Treatments Act (PATA; HR-1600) was introduced by representatives David B. McKinley (R-WV) and Lois Capps (D-CA) to limit cost-sharing requirements for specialty tier medications by reducing excessive out-of-pocket expenses.

Kuhn says PSI considers the use of specialty tiers to be enormously harmful to the patients it serves. "Specialty tiers can be designed to be discriminatory. What else would charging people more than they can afford for the medication they need do?" Kuhn asks. "Not only [can the use of specialty tiering] be discriminatory, but it is a backdoor way to discriminate against people with pre-existing conditions."

Prior Authorization

Cost-control methods such as specialty tiers can limit your access to your preferred factor brand and can cost you a lot out-of-pocket. Other methods just make it harder to get the medication and services you need. Prior authorization requires a healthcare provider to obtain permission from an insurer before prescribing a certain brand of medication or type of service. This process allows the insurer

12. Julie Appleby, "Workers Squeezed as Employers Pass Along High Costs of Specialty Drugs," *Kaiser Health News*, Aug. 22, 2011. 13. D. P. Goldman, J. F. Joyce, J. J. Escarce, et al., "Pharmacy Benefits and the Use of Drugs by the Chronically Ill," *JAMA* 291 (2004): 2344–50. 14. L. Osterberg and T. Blaschke, "Adherence to Medication," *New England Journal of Medicine* 353 (2005): 487–97. 15. For example, for an individual in 2015, the out-of-pocket limit is \$6,600. With expensive biologic drugs, a patient whose medication is on a specialty tier may have to pay \$3,300 out-of-pocket for that medication in January and another \$3,300 for it in February to reach his out-of-pocket maximum.



to determine whether a patient is eligible under its plan for coverage of the service or drug being prescribed, under what benefit the service or drug is covered, whether the service or drug is medically necessary and appropriate, and where and how the patient should receive the service or drug. All these decisions are made by the insurer, according to the health insurance policy you hold.

"Patients experience their disease as an individual; doctors treat them as an individual, with unique needs and history," says Donovan. "Insurers should respect this relationship, and also recognize that treating a patient with the right drug without the need for prior authorization for them will ultimately drive down costs and result in a healthier patient population."

Recently Angel Parrett, who has factor I deficiency, faced a prior authorization dilemma that left her without factor. This happened just as she was moving from an ACA Marketplace insurance plan to a group plan. "My hospital has a policy that they cannot order my factor without preauthorizing it with my insurance," Parrett explains. "They supposedly put it in as an 'urgent' request (within 48 hours) and it still took six or seven days for approval." Parrett, who is on prophylaxis, suffered a bleed because she couldn't receive her factor until the insurance company authorized her prescription. She didn't know that her new pharmacy thought factor was a routine medication given every two weeks, not every few days. It did not stock her factor, and ordered it only after her insurer authorized the order. "I wasn't going to give in and use cryoprecipitate," says Parrett, "but I started one morning with a bleed, so I made the clinic fit me in as soon as they could. At that point, the risk of waiting for authorization outweighed the inconvenience of using cryoprecipitate."

Step Therapy

Step therapy makes prior authorization look like a stroll in the park. Step therapy requires you to use the factor brand dictated by your insurer, not by your doctor or yourself. If the "first-step" selected factor brand isn't effective—perhaps it takes longer to control a bleed than your preferred brand—you can try a different brand, such as the one your doctor originally recommended. Patients who are forced by their insurer to undergo step therapy often must pay out-of-pocket coinsurance and copays for the medication they don't want to use and for medical visits to check the effectiveness of the first-step medication. Failure of first-step medication can cause physical suffering because a patient is not using an effective treatment for his or her individual needs.

The idea of step therapy as a means of managing bleeding disorders is not new. In 2004, when a major Medicaid HMO in Pennsylvania tried to use step therapy as a way to manage hemophilia, the local community was infuriated. "Step therapy is encroaching into treatment," said Ann Rogers of the Delaware Valley Chapter in 2005. "The payer determines what factor brand we should use, how many doses we should have, and when it is delivered. Medical treatment needs to stay with the medical team, and payers need to stay in the payer arena. Costs should be looked at, but as a team."¹⁶

In many states, patient advocacy groups have successfully passed or are working to pass legislation that prevents insurers from using step therapy as a cost-control measure, to prevent patients from enduring physical and financial hardships.

Human Shields?

"Specialty tiers, prior authorization, and step therapy not only are barriers to care, but they are also barriers within the patient-doctor relationship," Donovan

believes. "Doctors know their patients and understand far more intimately what may work for that individual in a way that renders any prefabricated formula comparatively less effective."

We rely on our HTC's and hematologists to provide the best care for bleeding disorders. Despite this proven expertise, and despite a wave of factor products on the horizon, neither you nor your doctor ultimately control whether you receive your preferred factor brand. This lack of control may impinge on the quality of care doctors can provide patients, and may affect patients' quality of life.

"Insurers blame the high cost of factor on the pharmaceutical companies that manufacture it; pharmaceutical companies blame insurance companies for making expensive drugs like factor inaccessible," says Kuhn. "The patients get caught in the middle and are being used as human shields in the blame game between the two industries. Patients themselves have no control over pricing, and they are the ones who are the ultimate losers in the fight. The pharmaceutical industry and the insurance industry need to figure out together how to get what both need while serving patients, who are the most important and vulnerable party among the three."



16. Kelley, "The Coming Storm."

Be Vigilant, Be an Advocate

Through patient advocacy efforts, much has changed in the US healthcare system since PEN's 2005 article. Much, despite legislation at the state and federal levels including the ACA, has stayed the same. Cost control remains the leading obstacle that prevents patients from obtaining their preferred factor brand. So along with understanding your coverage, it's essential for you to continue monitoring your insurance policy: check for rising deductibles, specialty tiering, prior authorization, step therapy, and the calculation of out-of-pocket costs to exclude deductibles, copays, or coinsurance. "We encourage active involvement and understanding of your personal health insurance policy," stresses Kimberly Haugstad,

executive director of Hemophilia Federation of America (HFA). "We advise community members to read their policy carefully and ask their insurer questions to minimize surprises." Check with your HTC social worker to help you through the healthcare cost monitoring process.

On a larger scale, join with your local hemophilia organization, National Hemophilia Foundation (NHF), and HFA as they work with legislators to control healthcare costs while preserving access to therapies that patients need. Check out NHF's Personal Health Insurance Toolkit for health plan comparison worksheets and a list of consumer resources.¹⁷ Travel to Washington, DC, to speak with your congressional representatives with HFA's Community Fly-ins and NHF's Washington Days.

Most important, stay vigilant. Carefully read your insurance policy annually, and watch for any barriers that might prevent you from getting the factor brand you prefer—and may need.

Wendy Owens is director of research for HFA. She has substantial experience advocating on healthcare-related issues, hemophilia treatment, and patient rights at the national and state levels. She lives in Washington with her husband and four children.



17. www.hemophilia.org.

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Finding the appropriate skilled nursing facility takes time and resources, so be prepared. Educate yourself, payers, and the SNFs, keeping these considerations in mind:

ACCESS

Post-acute care comes at a cost. When thinking about the type of care you need, determine who pays for what services, in what setting, and when.

1. *Who pays: Types of insurance*

Public

- Medicare
- Medicaid
- Dual

Private

- Individual plan
- Employer sponsored

Public-private combination

2. *Type of care needed: Depends on the situation*

3. *Settings: Facility types and locations*

Locations of acute care facilities include

- Hospitals
- Nursing homes
- Rehabilitation hospitals
- Hospice centers
- Long-term care hospitals (LTCH)
- Stand-alone facilities

Determination of placement depends on

- Amount of rehab therapy patient gets
- Patient's ability to perform activities of daily living

RESOURCES

Consider both financial and emotional resources. This process is hard on everyone: patients, families, and caregivers.

1. *Financial*

Short term
Long term

2. *Emotional*

Family, friends, caregivers
HTC social worker
Support groups

3. *Assistance and support services*

HTC providers (doctor, surgeon, physical therapist)
HTC case manager
Insurer
NHF's public policy team

under Medicare Part B for patients with hemophilia and other related bleeding disorders during an SNF stay. The rationale is that providing factor concentrate to patients is comparable to the specialized services Medicare recognizes as needing separate treatment.

Advocating for Change

In 2014, over 300 bleeding disorder patients and families went to Capitol Hill in Washington, DC, to advocate and educate on behalf of Medicare beneficiaries unable to access SNFs. They came close to having bipartisan legislation introduced. Over the next year, NHF will continue to find legislators who are willing to introduce a bill that would change how factor concentrates are reimbursed for patients in SNFs, allowing people with bleeding disorders to access these facilities. We hope this will happen before NHF's Washington Days in February 2016.

It's important to remember that passing legislation will take time, and will solve the issue of access *only* for Medicare patients who need to be placed in an SNF. Patients on Medicaid and private insurance (including employer groups, small and large group, and self-insured) may still have trouble accessing SNFs. We hope that once Medicare addresses the issue, Medicaid and private insurers will follow.

Based largely on their experiences with Medicare, and fearing the astronomical costs of bleeding disorder patients, SNFs are reluctant to accept even patients who have other insurance. NHF has successfully placed patients with different types of insurance in a variety of facilities, when we can work with the facility and explain how to properly bill for factor. Though not ideal, educating facilities about the unique needs of the bleeding disorder community helps ensure that patients can get the care they need.

Aging gracefully comes with its own set of challenges—especially for people with bleeding disorders. Coping with these challenges may be complicated, but the good news is that you're not alone: there are resources to help. NHF's public policy team has been hard at work trying to address how patients can best access the appropriate sites of care for the services they need. Although there isn't always a clear path with simple answers, our goal is to facilitate and help ease transitions, allowing all patients to age gracefully. —

For additional information about Medicare coverage of SNFs: www.medicare.gov/coverage/skilled-nursing-facility-care.html

Marla Feinstein is a policy analyst for NHF. She is instrumental in advocating for the bleeding disorder community at the national and state level. Her current efforts focus on ensuring access to care for people with bleeding disorders. She has presented on behalf of NHF at numerous national- and community-based meetings of government and industry stakeholders.

patients *are* able to fill an active script from another doctor when they first enroll with Sanitas to ensure continuity of care.

During these five weeks, I made numerous phone calls to Member Services; I was repeatedly disconnected, shuffled through a seemingly endless phone tree, or left voicemails that were never responded to.

When I was finally able to make appointments, I was told by Member Services that in order to see a hematologist, I first needed a referral from a primary care physician (PCP). I argued that I have hemophilia, a chronic bleeding disorder, and have records from a PCP visit within the last six months. This argument was fruitless; I had to see a PCP first. Later, I again learned that this is not Sanitas policy.

When I saw the PCP, I learned it would be at least another week until I could see the hematologist, and then another five days until the factor prescription written by this hematologist would be ready at the pharmacy. I asked if the PCP would write my prescription, but he wasn't comfortable with that. When I stressed that I was running out, he wrote a "holdover prescription" for one week's supply.

Got Factor?

When I tried to pick up the holdover prescription a few days later—because I'd already been told many times that Sanitas didn't provide home delivery—the pharmacy could not find my factor. One pharmacy employee actually said, "We lost it." I was shocked, but because the hematologist appointment was only a few days away, I decided to wait. My supply continued to dwindle.

At my hematologist appointment, I found myself in the role of teacher, explaining microbleeds, trough levels, and so on. The hematologist repeated

many of the same procedures the PCP had done, checking my blood pressure and heart rate. He didn't measure or closely examine my joints. For a company that prides itself on its data, I was surprised that this hematologist didn't measure anything. As the appointment ended, I received my full prescription for factor.

Days later, a pharmacy employee called. She had my factor, but she said that because my policy expired on March 31, 2014, she would not release it. I told her she was incorrect because my policy didn't even begin until April 1, 2014. She forwarded me to Member Services. After the phone rang for a solid five minutes—I'm not exaggerating; I timed it—I was disconnected.

Throughout, I made over 50 calls, spent over 400 minutes on the phone, and spoke to dozens of employees who gave me incorrect information about Sanitas's policy regarding newly enrolled patients, receiving chronic medication, home delivery options, the ability to see a specialist for a chronic condition, my account status, and my payment records.

Do I Have Your Attention Now?

Fortunately, I documented my entire experience, so when it became clear that I needed to take more aggressive action, I had detailed notes. I wrote a pointed, aggressive, but professional open letter to Sanitas and posted it on my Stop the Bleeding! Facebook page, then shared the post on my Twitter account and with my email list. In less than 72 hours, my letter received over 8,000 unique

reads. A senior staff member at Sanitas contacted me, and I requested an in-person meeting with various senior staff to discuss the litany of problems I had experienced.

The meeting was granted. I met with the medical director, pharmacy director, COO of clinical operations, and head of hematology/oncology. It was a semi-productive meeting. The senior staff heard my complaints and informed me of changes they'd already made to their "onboarding" new-patient enrollment process to better account for new patients with chronic diseases. The pharmacy director changed certain internal policies and implemented some education for her staff as a result of my complaints. She also agreed to put in writing that home delivery of factor for people with hemophilia was available on request. On the clinical side, I insisted that the overall quality of care was nowhere close to that offered by an integrated comprehensive care model such as an HTC, but it was clear they weren't interested in making clinical changes.



Instead, they insisted that the comprehensive care they offer is on par with an HTC's. When I insisted that the care was simply not equal, they agreed to "look into it," but nothing ever came of that.

Getting White-Glove Treatment

It's been roughly one year since that meeting. I'm receiving a tremendous amount of attention from Sanitas. Clearly, I'm the "problem child" and receive white-glove treatment so I don't cause any more PR headaches. Many flaws remain in Sanitas's system for people with rare, chronic conditions, not the least of which is uninformed Member Services reps who are often the first contact for new patients.



Fortunately, a focused effort is being led by two strong advocates in our bleeding disorder community who are collecting stories and organizing an action plan to effect reform at Sanitas.

Here are five guidelines everyone with a bleeding disorder should follow when engaging a new healthcare company or medical service provider:

1. You are the expert. It can be tempting to relinquish control and responsibility to an authority figure such as a doctor or pharmacy director, but you can't afford to. You must be an expert on yourself. It's your body. It's your life. Own it, take responsibility for it, and fight for what it needs.
2. Log everything. Many large companies and institutions have myriad people who answer phones or respond to emails; these people often work with minimal information, minimal accountability, and minimal incentive to go beyond the basic call of duty. Keep track of everything: names, dates, times, badge numbers—even the simple act of asking reps for this information subtly informs them that you are to be taken seriously, and if needed, you'll have a record of your experience.
3. Follow up again. And again. And again. Unfortunately, people don't always say or do what they claim they will. Keep at them. Don't allow uninformed or unmotivated employees to compromise your healthcare. Keep to your agenda until you receive the positive outcome you deserve.
4. Use our community. The bleeding disorder community is lucky to have empowered and educated advocates. I was overwhelmed by the number of people who offered to help me during my crisis. In this community, when you reach out, people will reach back. Don't

be ashamed to ask questions and ask for help. We're here for each other. We are each other's rock.

5. Stay positive and solutions-driven. No matter how noble the fight, nobody likes a rude, angry, or unprofessional fighter. It's important to be assertive, aggressive, and diligent, but it's unacceptable to be cruel or to behave inappropriately. If the system is broken, point out the flaws, and offer what you can to help fix it. We can't view these companies and their staff as enemies; they're not! They're our allies. But a lack of adequate education coupled with laziness, defensiveness, or irresponsibility can create catastrophe.

My experience facing a true, personal healthcare crisis was eye-opening, but I knew my own personalized healthcare needs, documented everything, stood my ground, and was able to articulate my needs to the company's executives. Being your own advocate is not an easy process, but it's manageable, empowering, and necessary. Always keep in mind that advocating for yourself is also advocating on behalf of everyone in our community. —

Patrick James Lynch, 29, has severe hemophilia A. He is co-founder and president of the digital content agency Believe Limited, through which he created and produces the award-winning hemophilia comedy series Stop The Bleeding! (stbhemo.com) and the inspirational speaker series Powering Through (poweringthrough.org). He's the 2013 recipient of HFA's Terry Lamb Award and the 2014 recipient of NHF's Loras Goedken Award. He lives in Los Angeles, California. Read an in-depth account of his experience at patrickjamslynch.com.

healthy. Because of the ACA, insurers are no longer able to refuse coverage to an individual; this means that many health plans have to address the needs of conditions they have rarely dealt with in the past, such as hemophilia. Sometimes barriers to certain products or services are the result of a lack of understanding about the condition and the needs of those affected.

Michelle's Tips

- Consider your health insurer a partner in your care rather than an adversary.
- Educate the insurer about bleeding disorders and the unique needs of you or your child.
- Obtain supporting documentation and expert opinions to help make your case.
- If necessary, reach out to your HTC, chapter, or NHF for assistance.
- Know your rights if a claim is denied.
- Remember, YOU are your best advocate!



Angel Parrett, Kentucky

Factor I Deficiency

LAST NOVEMBER, I SWITCHED FROM cryoprecipitate to factor concentrate to treat my bleeds. I also changed jobs, looking for a more normal schedule and

shorter commute.

Insurance through the new job required a 60-day waiting period for eligibility. I immediately contacted the HTC social worker to discuss my options for continuing to use factor, and using the clinic only to receive infusions. She suggested COBRA. We didn't realize that insurance through my previous job expired the day I left, on December 19, but the COBRA signup paperwork wasn't mailed until the beginning of January. When I arrived at my appointment on January 23, I learned I could be treated only in the ER. Eventually the new COBRA plan kicked in.

But the new job wasn't a good fit, so I reluctantly returned to my previous job. No insurance lapse from the end of March to mid-April, while I was changing jobs—but I was only there a few weeks before landing my current, new job, beginning April 16. Another 60-day waiting period. Unable to do COBRA again, I signed up for an ACA plan, which tied up my factor in preauthorization. So until further notice, I was stuck back on cryo.

In May I called the HTC social worker, who said the preauth was approved on May 8. Next, I had to convince the hospital pharmacy—which orders factor for outpatient infusions—that factor needs to be available at all times: they couldn't just order factor a few days before they expected me to show up, as they had been doing. I anticipated that this would be an issue in June, before I transitioned from my ACA plan to the group plan offered by my current employer beginning July 1. So in June, my hematologist instructed the pharmacy to have one dose on hand at all times. This allowed me to make last-minute schedule changes and still treat appropriately.

I was increasingly frustrated with the obstacles. The pharmacy and administration at my hospital don't see a patient

who deserves prompt treatment; they just care that someone is paying for the product.

Update: On July 1, I was to begin a plan with 80% coverage after a deductible of \$4,000 and a \$1,000 credit toward out-of-pocket costs. But in June, I was cut from my training program, and I no longer have a job. I have options for potential income, but I will be limited to Medicaid for now.

Michelle's Take

Unfortunately, many of the issues Angel encountered have been concerns for years and have become more noticeable to those with chronic conditions since the ACA passed. Why? Prior to the ACA, individuals with hemophilia and other rare disorders often did not have "options" when it came to accessing health coverage because insurers were not required to accept all applicants.

NHF has created a Personal Health Insurance Toolkit to help guide consumers through the process of evaluating insurance options. It appears that Angel followed these guidelines, but her story highlights the reality that even when you do everything right, there are still glitches. If you're purchasing your coverage through the Marketplace and have difficulty finding answers, contact a navigator in your area (find a list of state navigators on HealthCare.gov or your Marketplace's website) or the department of insurance in your state.

Michelle's Tips

- Start early.
- Make a list of your family's personal health history, including the names of physicians, hospital, and prescriptions.
- Don't be afraid to ask questions if you're unsure about a plan's benefits. —



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Inside:
Cost Controls and
Factor Access

September 2015

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