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Patients in Pain

A patient's first-hand account of problems with insurers **BY CYNTHIA TOUSSAINT**

CHRONIC PAIN attacks 76.2 million Americans each day. When those people visit their physician in search of treatments to help alleviate their suffering, many find their health plans prevent them from getting the prescriptions their doctors have deemed best. Some of the ways this is done include little-known practices such as step therapy, fail first and therapeutic switching.

Step therapy is when insurance companies force patients to try alternative treatments before allowing them to step-up to ones prescribed by their physician. A more egregious form of step therapy, called fail first, forces patients to “fail” on treatments not FDA-approved for their condition before being allowed to have their prescribed FDA-approved medication. Some patients are forced go through up to five alternatives. The danger of step therapy and forced off-label prescriptions is the possibility of continuing side effects, such as chronic pain or adverse reaction to medications with differing molecular structures.

As one of the millions suffering from chronic pain, I have experienced step therapy first hand. At age 21, I was an accomplished ballerina dancing five hours each day. My life changed drastically when chronic pain became a constant obstacle and eventually took over my life, shattering my dreams of ever dancing again. Since then, I have had countless doctor visits and spend most of my life searching for proper medication and treatment for Complex Regional Pain Syndrome and fibromyalgia, the two chronic pain diseases I've been challenged with for the last 26 years.

Eighteen years ago, my insurance company switched me from Axid, which I was using to treat CRPS in my vocal cords, to a cheaper medication. As a result, I couldn't speak and even experienced pain when whispering. I was forced to “fail” on two cheaper medications before getting the medication my physician originally prescribed. Similarly, my insurance company switched me from the brand name Klonopin, a medication I had been using for 15 years to rid my pain and anxiety, to a generic version—or so I thought. The next day, I was having withdrawal symptoms that included hallucinations, pain flares and intense anxiety. My doctor had to make an emergency request to get me back on my original medication. That was a frightening and traumatizing event; it taught me to ask lots of questions about generics.

While there is nothing wrong with switching to a *true* generic, many insurance companies use the term “generic” when they switch patients to a different medication altogether. This is called therapeutic switching. I reacted so negatively to the switch because I was given a medication with different chemicals and molecular structure.

Currently, my insurance company is forcing me to go off of Neurontin, which is used to treat my CRPS pain. They're about to switch me to the cheaper generic version, since Neurontin is no longer on their formulary. I was bedridden with CRPS pain for nearly a decade, and it was Neurontin and physical therapy that got me sitting up in my wheelchair and walking short distances. Today, I still can't get

authorization to stay on the brand name. I don't want to be bedridden once again and lose the life I worked so hard to regain.

As the founder of For Grace, a non-profit devoted to ensuring the ethical and equal treatment of women in pain, I hear daily from this community. They talk to me about the burdens brought on by their suffering, such as not being believed, financial ruin and experiences with depression. Many tell me that instead of helping to find a cure, their insurance companies prevent them from getting one. These women are talking about step therapy and therapeutic switching practices, but they aren't familiar with the proper terms because they don't understand who and what is victimizing them.

That is why For Grace and Healthy African-American Families are co-sponsoring AB1144, legislation that would make it unlawful for healthcare providers and insurers to force patients to “fail” medications before receiving the one deemed necessary by their doctor. It would also prevent therapeutic switching.

While Americans are continuing to suffer, insurance companies are using them as guinea pigs, and many are unaware of the practices being used. Legislation would put an end to patients being forced to endure weeks, even years, of unnecessary pain, inappropriate treatments and increased healthcare costs. Californians must be aware of these issues and speak out to help prevent prolonged suffering for those in pain.

Cynthia Toussaint is founder and spokesperson for For Grace, www.forgrace.org. ■

FINDING FRIENDS

“**CRISIS BRINGS OPPORTUNITY.**” Where have I heard that one? As the government comes crawling up our leg, it is time to engage some people we once considered “enemies” to work collaboratively to maintain a private healthcare marketplace. Now is the time to stop suing health plans and spending CMA's hard-earned dollars on a new Mercedes for some attorney. CMA's successful RICO settlement taught us that there is nothing in these lawsuits for doctors, patients or the betterment of healthcare delivery.

How about talking with health plans to see what we can do *together* to further the health of patients and ease administrative hassles? We must insist that health plans stop playing doctor and

start meeting their obligations as insurers. We must insist that they sell insurance, not health benefits. Leave the benefit market to the marketplace, reduce the cost of insurance and let doctors work for their patients. That is our only opportunity to beat the government at its own game of “lowering cost” and “improving quality.” Failure to team up with powerful forces to rally for a competitive marketplace would leave us in a very lonely commodity market... as the puck in a rink with no goals. *Ouch...*

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