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Doctors, not pharmacy benefit managers, should be determining the treatment for my cancer

I was told that before the insurer would grant coverage for the treatment my oncologist felt was best for me, I had to try and fail on medications the insurance company preferred.

by Paul O'Hara, For The Inquirer

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Doctors, not pharmacy benefit managers or insurers, should determine what drugs a patient receives and in what order, Paul O'Hara writes. Chinnapong / Getty Images/iStockphoto

For the better part of two decades, I have been living with cancer. I'm grateful for the advances in treatment that have made that possible, but I also have faced denials and delays to my care that could have meant a different outcome for me.

In 2010, I went to the doctor with what I thought was the flu. I was having trouble sleeping, frequent heartburn, and a persistent cough. My life quickly took an unexpected turn when I was diagnosed with chronic myelogenous leukemia (CML), a cancer that starts in the bone marrow.

Again, the unexpected. Suddenly my family and I were navigating an unknown and scary world — multiple tests and treatments I couldn't spell, countless decisions, and most unexpectedly, despite having insurance coverage, wondering how we'd be able to afford the treatments to save my life.

For most of my adult life, like most people, I paid insurance premiums for my family, expecting that if my wife or I or one of my daughters gets sick, the money I've paid into that pool will be there to help cover what we need. But when I was diagnosed, I quickly realized this wasn't the case.

It turns out the insurance company had a treatment plan of its own for me, but not the one my actual oncologist had prescribed.

I was told that before the insurer would grant coverage for the treatment my oncologist felt was best for me, I had to try and fail on medications the insurance company preferred. That practice is called step therapy, and for cancer patients, it can be deadly.

I can't speak for everyone, but for me, failure is not really a word you want to be part of the discussion when it comes to cancer. The companies driving it, pharmacy benefit managers like OptumRx, Express Scripts, and CVS Caremark, profit from controlling what drugs get covered and in what order.

For patients with other blood cancers like chronic lymphocytic leukemia, the most common adult leukemia, the consequences can be even more severe. Delays and forced substitutions can allow the disease to evolve in ways that close the window on the best available treatment entirely.

If I had been diagnosed 10 years earlier, the treatment for CML would have included chemotherapy or a bone-marrow transplant. Today, thanks to medical advances, the most effective treatment option for my type of leukemia is daily oral anti-cancer therapy.

There are no comparable IV medications, and the self-administered pills allow me to continue to work and be an active person. In the last several years I've started running again, which has been a great outlet for me and another way to protect my health.

Thankfully, when my insurance tried to force me to try and fail on their alternative treatment plan, my oncology team was able to get me enrolled in a program with a drug company through which I'm able to get my medication directly from them and at low cost. But without that option, I could be forced to deal with my insurer and likely face delays and denials for my care.



Thanks to medical advances, the most effective treatment option for his type of leukemia is daily oral anti-cancer therapy, writes Paul O'Hara. Pongsak Tiantad/Dreamstime/TNS

Congress has an opportunity to stop this from happening to cancer patients, and everyone else who has been put through the dangerous process of step therapy.

The House Oversight Committee is already leading the charge. In a [letter](#) to Mehmet Oz, administrator of the Centers for Medicare and Medicaid Services (CMS), Oversight Committee Chair James Comer called on the centers to do more to protect Medicare Part D patients from insurer- and pharmacy benefit manager-imposed step therapy.

Part D plans are already bound by national cancer treatment guidelines that make clear not all cancer drugs are interchangeable, yet insurers and their pharmacy benefit managers routinely substitute treatments for financial reasons rather than medical ones. CMS has the tools to crack down and needs to use them.

Comer also played a critical role in crafting pharmacy benefit manager reforms. He and his colleagues should seize on the momentum of those successes by passing the [Safe Step Act](#), which would ensure patients can receive timely exceptions when step therapy is medically inappropriate.

I ask the Pennsylvania federal delegation to get behind the Safe Step Act.

The commitment to putting patients first should extend to ending fail-first policies that can delay access to the cancer treatments that physicians determine are most appropriate for their patients.

All cancer patients want is to live life to its fullest, to see the other side of their diagnosis, and to get back to knowing what to expect out of each day. Patients deserve to know that their health insurance will provide the care their doctors say they need. I ask the Pennsylvania federal delegation to get behind the Safe Step Act. It is vitally important to the lives of American patients.

Paul O'Hara is a Doylestown resident and the president of Connected Cloud LLC, an information technology consulting firm specializing in cybersecurity.