

# Dangerous Health Care Middlemen & Bureaucracies: Pharmacy Benefit Manager Horror Stories — Part V



**T**he Pharmacy Benefit Manager (PBM) industry lobby claims that it successfully achieves drastic price reductions on medications. They say this comes from PBMs negotiating with competing drug companies and by “encouraging consumers to use the most cost-effective drugs.”

Setting aside clear evidence that secretive PBM rebates and fees are actually driving drug prices higher, the last claim should give all Americans pause. How exactly does a PBM “encourage” a treating physician to use cost-effective but life-saving drugs? How do they know what is right for each individual patient and disease? What tactics or methods do PBMs use to do this? And are the changes in the patients’ best interests, or simply to save money for PBM profit margins?

Unfortunately, time after time, PBMs have been exposed for abusing their position to do this, getting between the patient with cancer and their physician to dictate care. All too often, the PBM bureaucracy does this by simply and heartlessly delaying or denying make patients’ access to needed medications. Perhaps most egregiously for patients facing a ticking clock of cancer, PBMs deny prescribed treatments and demand that patients first fail on a list of ‘approved’ drugs before receiving the medication that their physician prescribed in the first place.

For patients with cancer, this intrusion into their care plans is painful, potentially life-threatening, and unnecessarily stressful. For oncologists it is yet another bureaucratic burden placed between them and caring for a patient, wasteful of scarce health care resources, and insulting to the doctors that went to medical school and prescribe treatment plans.

These and other monstrous by-products of the PBM system are further exposed here, as the Community Oncology Alliance (COA) presents the fifth in a series that focuses on the very real and negative impact PBMs continue to have on patients with cancer today. The infuriating stories presented here are real but made anonymous with personal details changed to protect the privacy of the patients.

## **A NARROW WINDOW FOR TREATMENT**

Brian, a married social worker with two young children, was in his early 30s in February 2014, when he was diagnosed with a relatively rare form of cancer in his appendix. Brian underwent surgery and chemo at a large hospital system, and for the next few years, his life went back to normal.

In late 2017, however, Brian suffered a relapse. He underwent surgery to remove all traces of the cancer, and his oncologist followed up with a round of chemotherapy. Despite the metastasis, Brian’s doctors thought he had a good chance at survival, and recommended that he

immediately begin a six-month regimen of oral medication to help keep the cancer at bay. He was young, strong, and had everything to live for; they were optimistic the cancer might never return.

On February 8th, Brian’s oncologist sent a prescription for the pills to the local pharmacy his clinic worked with. They informed him that while they had the medicine in stock, Brian’s insurance and PBM prohibited them from filling the prescription. Instead, they forwarded the prescription to a PBM-mandated specialty pharmacy to receive prior authorization.

The PBM-mandated specialty pharmacy granted the prior authorization, but was also unable to fill the prescription, so it was forwarded to yet another PBM specialty pharmacy. By this point, 11 days had passed. After another few days of silence, the second PBM pharmacy sent a message that they were unable to fill the prescription; it had to be done by the first PBM specialty pharmacy. It seemed that no one really knew who was responsible or able to fill the script.

On February 23rd, the same day that Brian finally received his oral anti-cancer medications, he was rushed to the emergency room for severe pains in his abdomen. There they discovered he had contracted an infection that necessitated surgery to repair his abdominal wall. The pills in his hand were no longer relevant.

Today, Brian must remain on chronic antimicrobial therapy pills to ward away abdominal infection; should he stop, they might easily return. Unfortunately, this precludes any further chemotherapy, and Brian's once promising prognosis has been replaced by one far direr. In effect, Brian missed his very narrow window and it is likely that he will never get well again.

*Oncologists are on the front lines treating patients with cancer who have complex needs – they know the exact state of their patients, and how very precious even a day can be. PBMs and their mandated specialty pharmacies are several times removed from the exam room, and as a result, their lack of urgency and inability to cut through bureaucratic red tape can easily become an indirect – or even direct – cause of patient suffering.*

## **NOT A HEALTH CARE PROFESSIONAL? YOU DON'T STAND A CHANCE**

After having survived her battle with thymus cancer in 2015, Rachel was surviving with several autoimmune disorders, including myasthenia gravis, a condition in which the body attacks its own neuromuscular connections. After utilizing several immunosuppressants, Rachel has managed to keep the illness in remission for the past two years, by taking a wonder drug that works as an immunosuppressant, maintaining a low volume of antibodies in her system.

An advanced oncology certified nurse at a community oncology clinic, Rachel knows her condition well and how to stay healthy. For two years she has been taking her

medication faithfully every day, working to care for her patients, and living life as normally as could be.

Then, at the beginning of 2019, her employer changed insurance carriers. When it came time one Friday for Rachel to refill her meds, she went to the local pharmacy to pick them up, only to be told that there were 'issues.' The pharmacist was confused and said he would look into it.

Two hours later, the pharmacist called to say that from now on, Rachel must obtain her medication through the PBM's specialty pharmacy. She immediately called the new pharmacy's number, where she waited a long time until she was connected. After trying fruitlessly to locate Rachel in the system, he put her on hold for ten minutes. When someone else finally came back online, Rachel had to tell her entire story from the beginning. This happened several times, with Rachel's blood pressure rising exponentially. It was Friday afternoon, and she had six pills left – enough for two days.

Rachel hung up the phone; this had been a dead end. Falling back on a trick she had learned after dealing with countless PBM bureaucracies on behalf of patients, Rachel called the member services number on the back of her insurance card. After being passed around from representative to representative, she reached "Brian," who promised to establish a new member's account for her. However, as to her refills, he insisted he first needed to call her doctor to get prior auth.

Rachel began to see red. It was Friday afternoon, and her neurologist's office was closed. Trying to remain calm, Rachel explained to Brian that she still had several refills left. Brian promised he would contact her pharmacy and have the refills transferred over. "Call me in the morning," he said. Saturday morning, at 7:30 am, she called the specialty pharmacy, where she was told that no one named Brian had been in touch, and there was nothing in the computer about her issues. However, this new representative was the real deal. She handled everything over the next few hours, and arranged for the meds to arrive by Monday – which they finally did – just as Rachel's pills had run out.

*Infinite patience coupled with buckets of determination and self control seem to be de rigueur when it comes to dealing with PBM Specialty Pharmacy bureaucracies holding one's life-saving medicine hostage. If it was this difficult for a seasoned, tough-as-nails advanced oncology nurse to get her own meds, what is going to happen to the other 99.9% of the population?*

## CLERICAL ERRORS MARRIED WITH INCOMPETENCE

Paula was a very intelligent company executive battling breast cancer. Her oncologist prescribed a particular medication and she faced no issues in having it filled or refilled the first time. When it came time for the second refill, however, she met a PBM roadblock. Despite several calls to the PBM, and speaking with several different people, all the patient could get them to explain was that there were insurmountable “insurance issues.” Not knowing what else to do, she came into the oncologist’s office so they could call the PBM together to resolve the matter.

After a long wait on hold, the doctor and his patient finally reached a representative who informed them that they were unable to fill the prescription because it could have a negative interaction with another medicine she was currently taking. The doctor and the woman looked at each other for a moment, before asking the rep, “What medicine?” The patient was not taking any other medication. This was, however, not what the PBM had in their records. It took quite a bit of additional convincing by the patient and her doctor before the PBM would believe them, and agree to provide authorization.

By this point, due to clerical error and the absence of anyone to take responsibility, the patient had already gone 10 days off of her regimen, something which never should have happened.

*Practices report that they spend an absolutely ‘ridiculous’ amount of time trying to obtain prior authorizations from PBMs – well beyond any reasonable expectancy. Even getting to the point where there is another human being on the other end of the phone to talk to is an achievement in and of itself. This, of course, is only the beginning of the PBM process that is fraught with errors and poor record keeping, all of which can add up to dozens of hours of staff time wasted dealing with bureaucracy, and drag on over days, weeks, even months. In the meantime, patients with cancer are left waiting without the treatment that they need.*

## PBM<sub>s</sub> SERVING THEIR OWN BOTTOM LINE

Gordon, a retired FBI agent with a distinguished record of security service on behalf of the United States, was diagnosed with an aggressive form of lung cancer. Proving resistant to the drug regimen his oncologist initially prescribed, the cancer metastasized to his brain, and he was immediately started on radiation therapy. It was at that point that his doctors made an important discovery: Gordon’s cancer had the EGFR mutation, which indicated he would do better with oral medication than infusion chemotherapy. More importantly, there was a new drug that had just been approved by the FDA as the first-line treatment for EGFR-mutated non-small cell lung cancer. This gave Gordon and his cancer care team a window of hope.

Gordon’s oncologist prescribed the new medication, but the PBM denied authorization, providing the name of an alternative drug they wanted him to try first. His doctor argued that his original prescription would be better for the patient; It had been shown to have far higher efficacy for patients whose cancer had metastasized to the brain. The PBM argued back that it had been initially approved for a different EGFR mutation than the one Gordon had. His doctor argued back that this was irrelevant, as it was effective for Gordon’s mutation as well, and was now FDA approved.

Back and forth, the fight went on for an entire month, with the doctor providing data and rationale to support his clinical decision making. Meanwhile the cancer grew inside Gordon, unchecked. He began to feel increasingly fatigued, and a man who had remained very active throughout his cancer battle began to deteriorate.

Ultimately, after more than 30 days of wasted time, the PBM approved the doctor’s original prescription. Upon beginning the regimen, Gordon’s condition began to slowly improve, but it never should have been allowed to reach such a low state.

*Again and again, we see PBMs playing doctor, choosing to authorize one medication and not another, for reasons that have nothing to do with patient care. From pushing the drugs from pharmaceutical companies with which they have made sweetheart deals, to demanding patients be*

*prescribed lower-cost medication, their actions are profit-driven and often in complete contradiction to what the patient actually needs to get well.*

## **PBM APATHY LEAVES BOY IN DANGER OF BLEEDING TO DEATH**

Diagnosed with hemophilia, 15-year old Jason had to simultaneously contend with his blood's inability to form clots and the danger of bleeding uncontrollably. Jason's oncologist had him on a once-daily oral medication that can slow the spread of his cancer by blocking a specific protein the disease needs to thrive.

One day, Jason missed his footing on the stairs at home. Falling, he hit his thigh and developed a significant hematoma, common with hemophiliacs. He now urgently needed a specific recombinant factor injection to help his blood clot, and quickly.

Jason's oncologist quickly prescribed the necessary self-injected medication to be taken at home. Prior authorization was received, however the PBM handling Jason's case refused to allow the practice's pharmacy to fill the script, so they forwarded it to the PBM-mandated pharmacy. Unfortunately, they could not fill the prescription, and without informing Jason or his doctor, they outsourced the prescription to yet another pharmacy.

Recognizing the urgency of the situation, Jason's mother, a full-time nurse, stepped in to see how things could be expedited. She made numerous phone calls, verifying that the pharmacy she used to work with before her insurance changed had the medication in stock and, due to a contract with the PBM, was able and willing to ship it out the next day. Not wanting to lose out on the business, the original PBM-mandated pharmacy stepped in and vetoed the plan, stating that as it had already been ordered from them, there could be no cancellations.

Adding another layer of unnecessary problems to the mix, the PBM suddenly claimed that there had been no prior authorization filed for the prescription. Undeterred, the practice pharmacist spent hours trying to get it all done as soon as possible, so that Jason could get the medicine he needed.

Finally, just when it felt like the situation was starting to be resolved, the PBM pharmacy representative on the phone belatedly realized that the medication in question was for injection and stopped the process. Prescriptions for injections, she said, had to go through a different department. Unfortunately, it was now 5 pm on a Friday and the PBM offices were closed for the weekend, so they would have to wait to submit the prescription until Monday. Because of his hemophilia, young Jason was now in danger of developing a dangerous complication that could require emergency surgery and a long hospital stay if not treated immediately.

With no alternative, the doctor sent Jason to the hospital emergency department to receive the necessary injection. While this prevented any life-threatening occurrences, it incurred an enormous expense for his family and insurer, one that could easily have been avoided. Due to the astonishing bureaucracy, a patient fell through the cracks, with no one outside his personal doctor standing up to take responsibility or showing the slightest concern.

*Patients do not walk off the pages of a textbook or an encyclopedia of illnesses and their recommended treatment. Each case is individual and ought to be treated as such, in a thoughtful, intelligent, holistic manner. Additionally, patients do not stop treatment just because it is the weekend or after the phone lines shut down. The more control PBMs are given over patient care, the more sweeping and infuriating their bureaucracies become, and, ultimately, the more dangerous their decisions and actions prove to be.*

## **WOULD YOU LIKE SOME KIDNEY FAILURE WITH YOUR CANCER?**

In the Fall of 2012, Trisha, a medical software instructor in her early 60s, suffered renal failure and was rushed to the hospital. Diagnosed with Multiple Myeloma, she underwent dialysis and was referred, by her community oncologist, to a Myeloma specialist at the nearby hospital system. The specialist recommended a particular regimen of chemotherapy to keep the disease in check, and Trisha was released.

A few months later, tests revealed that the cancer was progressing. Her chemo was clearly not working; a new

medication had to be tried. This would not be simple, for following Trisha's renal failure, her kidneys had never returned to normal. This meant her doctors had to be extremely careful about what drugs they prescribed, as certain medications for Myeloma are known to take a heavy toll on the kidneys.

Trisha's oncologist, in consultation with the hospital specialist, decided to prescribe a particular drug that could slow the progression of her disease, without having any adverse effects on her already stressed kidneys. Her oncologist sent in the prescription to the PBM mandated specialty pharmacy, which promptly sent back a notice denying the request.

At first, the pharmacy said that prior authorization was needed. Her doctor said, "No problem," and instructed the in-house clinic to fill out all the necessary forms and fax them over. This was followed by a second denial, which stated that the patient did not meet "the proper requirements" to receive the requested drug. What were those requirements? Trisha had to first have tried two other drugs, one after the other, and to prove that either her body had been unable to tolerate them, or that they had failed to slow the cancer's advancement.

Of those two drugs that the PBM demanded Trisha try - and fail - first, one was the very same drug she had been prescribed the previous year that had already failed to slow the cancer's progression. The second was a medication that, had she taken it, would have seriously damaged her kidneys and likely put her back into renal failure.

Over the next two months, Trisha's oncologist appealed the PBM's decision, and a long series of communications ensued between the oncologist, the Multiple Myeloma specialist, and the PBM specialty pharmacy. Trisha, meanwhile, watched with increasing anxiety as her myeloma protein markers quadrupled, indicating that the cancer was gaining ground. The appeal turned into a letter of medical necessity, and ultimately, after more than two months of delay, the correct medicine was finally approved by the PBM.

***PBMs have been given enormous amounts of control over what doctors may and may not prescribe. They try to strong-arm doctors into prescribing the medicine***

***that the PBMs choose, even though they have never met the patient, and often have no medical background to support the decisions they are making.***

## **PBM DELAY TACTICS VICTIMIZE PATIENTS**

Belinda, a kindergarten teacher and mother of two, was fighting thyroid cancer. Her oncologist had her on a particular medication that was approved for off-label use on thyroid cancer; she'd been taking the medication for seven months and was doing well.

In January, Belinda's insurance carrier moved to a new PBM, which required her to fill her prescriptions at their mandated specialty pharmacy. They assured Belinda that it would be no trouble for them to continue filling her medication. So, that same month, when it came time for Belinda's refill, her oncologist sent the e-prescription directly to the new pharmacy, and called Belinda to confirm.

When Belinda tried to pick up the prescription, however, the PBM-mandated pharmacy said they were unable to process it "at that time." She waited an entire month before being contacted by the PBM pharmacy to verify benefits and schedule delivery. After another week went by with no medication, a very frustrated Belinda called her oncologist to see if they could dispense the medication directly to her. Unfortunately, according to Belinda's insurance policy, they were not allowed to do that.

Another week passed, and, after six weeks of delays, the PBM-mandated pharmacy contacted Belinda. They wanted now to schedule delivery – again. The prescription was then sent to PBM's Clinical department to verify dose, diagnosis, allergies, and drug interactions.

At this stage, someone at the PBM finally noticed that the drug was being prescribed for an off-label usage, and called her oncologist to verify the diagnosis. The oncologist spoke to the PBM pharmacist, explaining that the drug had been approved for nearly a year, with the patient taking it all that time, to very beneficial results. It had always been for off-label usage, and the insurance company had always agreed to it. What was the matter?

The PBM pharmacist had no explanation for the time lag, nor was there any documentation to explain why more than two months had passed. At the end of the

conversation, the doctor asked if Belinda could finally expect to receive her medication now. “No,” the pharmacist replied. “Now, we forward the matter to the payment verification center. After that stage, it will be forwarded to the dispensing center. Then we can ship it out.”

Had Belinda been authorized to purchase her medicine from the in-house pharmacy at her doctor’s office, the entire process would have taken a single day.

*The larger an organization, the more complex the bureaucratic procedures. This is often done under the guise of ensuring safety. However, how far do things need to go before it can be said that the harm to patients has greatly surpassed any intended good? At what point do the PBMs themselves become accountable to a certain standard of care – even in terms of something as simple as response time?*

### **IT IS TIME TO STOP PBM ABUSES!**

While much of the debate over PBMs focuses on economics, there is often not enough discussion about the impact PBMs have on patients. The sad fact is that PBMs make more money by delaying or denying patients access to necessary medications. Every pill they stop from being dispensed is money they can pocket. COA has documented real-life patient horror stories from practices and physicians about patients battling cancer who have suffered at the hands of PBMs due to delayed coverage decisions, denial of coverage, arguments with physicians over proper treatment, and failure to receive medications in a timely manner.

Read our other PBM Horror Stories papers at <https://www.communityoncology.org/category/horror-stories/>

## **About the Community Oncology Alliance**

*The majority of Americans battling cancer receive treatment in the community oncology setting. Keeping patients close to their homes, families, and support networks lessens the impact of this devastating disease. Community oncology practices do this while delivering high-quality, cutting-edge cancer care at a fraction of the cost of the hospital setting. The Community Oncology Alliance (COA) advocates for community oncology and smart public policy that ensures the community cancer care system remains healthy and able to provide all Americans with access to local, quality, affordable cancer care. Learn more at [www.CommunityOncology.org](http://www.CommunityOncology.org)*