WHEN COVERAGE FAILS

Patient experiences navigating insurance barriers to care

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Behind the Denial: The Patient Experience

Across the country, patients and families face growing challenges navigating the health insurance system—even when seeking treatments prescribed by their doctors. Administrative barriers such as coverage denials, prior authorization delays, specialty pharmacy restrictions, and rising out-of-pocket costs can disrupt care for patients managing serious and chronic conditions.

The following pages contain real patient experiences submitted to congressional offices, advocacy organizations, and policy stakeholders. These stories show how insurance practices can delay treatment, increase financial strain, and create uncertainty for patients who rely on timely access to care.

While each patient's situation is unique, common patterns emerge: delays in care, coverage decisions that override physician recommendations, restrictions on medication access, financial barriers, and limited availability of behavioral health or specialty services.

For patients managing conditions such as cancer, autoimmune disease, bleeding disorders, and substance use disorders, even brief disruptions in care can have serious consequences. Each story illustrates the human impact of these systemic challenges.

Disclaimer

The patient experiences included in this document are drawn from stories voluntarily submitted to congressional offices, advocacy organizations, and policy stakeholders. Quotations reflect the patients' own words and have been lightly edited for length and clarity while preserving the original meaning and intent. Names and identifying details have been changed to protect patient privacy.

Opioid Use Disorder

California

“They make billions off the backs of patients, yet refuse to cover the proven, evidence-based treatments we need to thrive, like behavioral health care and MAT.”

Condition:

Opioid Use Disorder

Issue:

Limited access to in-network providers & forced medication substitution

Summary:

After switching insurance plans, the patient struggled to locate in-network providers for medication-assisted treatment (MAT). She now pays $250/month out-of-pocket for essential behavioral health care. Additionally, the insurer attempted to force her onto an alternative medication that had previously failed, with minimal time to appeal.

Impact:

Insurance network limitations and formulary substitution policies jeopardize continuity of care and increase out-of-pocket costs.

Hemophilia Parent

Delaware

“PBMs divert cost savings meant for patients into their own hands, provide no choice or transparency, and ignore patients’ needs. This is wrong!”

Condition:

Hemophilia

Issue:

Co-pay accumulator programs and PBM manipulation

Summary:

The caregiver’s son requires a drug costing nearly $185,000 per month. His insurance and PBM dictate which specialty pharmacy to use and block access to a drug that could reduce infusion frequency. Copay assistance from the drug manufacturer was denied credit toward his deductible, forcing the family to cover thousands of dollars out-of-pocket to receive necessary treatment.

Impact:

Administrative manipulations and restrictions created financial strain and threatened consistent access to life-saving medication.

Bleeding Disorder Patient

Florida

“Copay accumulator programs make it harder for patients with chronic and rare diseases to afford life-saving care. They undermine treatment adherence, increase stress for families, and threaten the independence patients work so hard to achieve.”

Condition:

Rare, Chronic Bleeding Disorder

Issue:

Copay accumulator programs and financial barriers

Summary:

Preventive treatment alone costs the family over $60,000 per month. The insurance company refuses to count copay assistance toward their deductible or out-of-pocket maximum, leaving patients responsible for full cost-sharing amounts despite manufacturer support.

Impact:

Financial barriers threaten adherence to life-saving treatment and add stress for families managing chronic conditions.

Epilepsy Patient

Indiana

“This process undermines the patient-provider relationship. Insurance companies should not override or second-guess clinical judgment.”

Condition:

Epilepsy (Chronic life-long seizures)

Issue:

Prior authorization and insurer-required medication changes

Summary:

A patient living with seizures since childhood worked with her neurologist over many years to identify a medication that effectively controlled her seizures with manageable side effects. When her doctor prescribed the medication that had proven most effective, her insurance plan denied coverage and required her to try insurer-preferred drugs first.

Impact:

Access to a stable treatment plan was delayed, creating uncertainty and stress while managing a serious neurological condition.

Ankylosing Spondylitis Patient

Idaho

“Restricting access to effective therapies like physical therapy leads to higher long-term costs for both insurers and taxpayers—costs that could be reduced through proactive, evidence-based coverage decisions.”

Condition:

Ankylosing Spondylitis (Chronic Inflammatory Spine Disease)

Issue:

Physical therapy visit denials & pre-approval requirements

Summary:

The patient relies on physical therapy to maintain mobility and manage pain. Despite coverage for the same number of visits, pre-approval requirements led to repeated denials. He was forced to pursue more expensive alternatives and faced further delays even after an ACL injury, when an MRI was denied until six weeks of physical therapy were completed.

Impact:

Insurance decisions overrode his doctor’s clinical judgment, increasing health risks and administrative burden.

Cancer Care Parent

Louisiana

If I, a healthcare CEO with a full understanding of the system, couldn't break through this wall of bureaucracy for my own child, what hope does any other American have?"

Condition:

Young Adult Cancer Patient

Issue:

Delayed medication approvals by PBM

Summary:

A cancer center CEO's daughter faced delays for a standard-of-care medication. Despite professional expertise and persistence, it took 10 weeks to access the treatment, which was initially delayed by PBM bureaucracy despite urgent medical need.

Impact:

Even knowledgeable caregivers were unable to overcome PBM delays, illustrating systemic barriers that affect all patients.

Cancer Care Physician

Maryland

“This is just the tip of a very unscrupulous and unethical iceberg of specialty pharmacy machinations.”

Condition:

Multiple Myeloma & Metastatic Colorectal Cancer

Issue:

Specialty pharmacy mismanagement, repeated call transfers, and false information

Summary:

Per a prominent oncologist treating cancer patients, his patients faced repeated miscommunication and misinformation from PBM-mandated specialty pharmacies, including disconnected calls, inconsistent policies, and refusal to dispense partial medication doses despite manufacturer protocols.

Impact:

System failures threatened timely access to life-saving cancer therapies, wasting time and resources.

Cardiac Patient

Massachusetts

“Most transplant patients do not have the advantage I had. Navigating insurance is not merely frustrating — it is a profound threat to timely, appropriate care.”

Condition:

Advanced Heart Failure / Heart Transplant

Issue:

Delays due to prior authorization and complex insurance processes

Summary:

The patient experienced repeated obstacles while awaiting his heart transplant 15 years ago. Prior authorization requirements and opaque insurance processes made it extremely challenging to navigate lifesaving care. Even after being listed for transplant, he relied on a personal ombudsman assigned by his insurer to help manage barriers — a resource most patients do not have.

Impact:

Insurance delays, restrictive networks, and administrative hurdles add stress and risk for patients with life-threatening conditions. For those awaiting a heart transplant, timely access to care can be a matter of life or death, and navigating the system without support can jeopardize treatment outcomes.

Gastrointestinal Patient

Texas

“I would have had to pay $800 per month out of pocket for the medicine that had been previously covered and that my doctor initially prescribed, which is absolutely ridiculous.”

Condition:

Gastrointestinal Disorder / Post-Surgical Care

Issue:

Coverage delays, prior authorization denials, substitution of prescribed medication

Summary:

A patient in Austin recently faced extensive health challenges, including two unexpected surgeries within a two-month period. During recovery, she encountered repeated delays and administrative hurdles from her insurance provider. Additionally, a prescription for a medically necessary gastrointestinal medication was denied three times, forcing her to accept a less effective alternative or face paying $800 per month out-of-pocket.

Impact:

Administrative barriers, prior authorization requirements, and restrictive coverage practices can delay critical care, force patients to use suboptimal medications, and impose significant financial burden—particularly for patients managing complex or post-surgical conditions.

Call to Action: Patient-Centered Reforms

The stories in this binder illustrate consistent challenges patients face in accessing medically necessary care, including delays due to administrative requirements, coverage denials that override clinical judgment, restrictions on where medications can be obtained, and financial barriers despite insurance coverage.

These experiences highlight the need for policy solutions that prioritize patients and support timely, evidence-based care.

Congress can take action by:

- Ensuring coverage policies do not delay or deny medically necessary treatment
- Strengthening protections for patient access to prescribed therapies
- Increasing transparency and accountability in insurance and PBM practices
- Reducing administrative burdens that create unnecessary obstacles to care

By addressing these issues, Congress can help create a healthcare system that is efficient, predictable, and centered on patient needs, enabling patients to receive the treatments their doctors prescribe without undue delays or barriers.