

## Doctors and patients try to shame insurers online to reverse prior authorization denials

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Sally Nix was furious when her health insurance company refused to pay for the infusions she needs to ease her chronic pain and fatigue.

Nix has struggled with a combination of autoimmune diseases since 2011. Brain and spinal surgeries didn't ease her symptoms. Nothing



worked, she said, until she started intravenous immunoglobulin infusions late last year. Commonly called IVIG, the treatment bolsters her compromised immune system with healthy antibodies from other people's blood plasma.

"IVIG turned out to be my great hope," she said.

That's why, when Nix's <u>health</u> insurer started denying payment for the treatment, she turned to Facebook and Instagram to vent her outrage.

"I was raising Cain about it," said Nix, 53, of Statesville, North Carolina, who said she was forced to pause treatment because she couldn't afford to pay more than \$13,000 out of pocket every four weeks. "There are times when you simply must call out wrongdoings," she wrote on Instagram. "This is one of those times."

Prior authorization is a common cost-cutting tool used by health insurers that requires patients and doctors to secure approval before moving forward with many tests, procedures, and prescription medications. Insurers say the process helps them control costs by preventing medically unnecessary care. But patients say the often time-consuming and frustrating rules create hurdles that delay or deny access to the treatments they need. In some cases, delays and denials equal death, doctors say.

That's why desperate patients like Nix—and even some physicians—say they have turned to publicly shaming insurance companies on <u>social</u> media to get tests, drugs, and treatments approved.

"Unfortunately, this has become a routine practice for us to resort to if we don't get any headway," said Shehzad Saeed, a pediatric gastroenterologist at Dayton's Children's Hospital in Ohio. In March, he tweeted a photo of an oozing skin rash, blaming Anthem for denying the



biologic treatment his patient needed to ease her Crohn's disease symptoms.

In July, Eunice Stallman, a psychiatrist based in Idaho, joined X, formerly known as Twitter, for the first time to share how her 9-month-old daughter, Zoey, had been denied <u>prior authorization</u> for a \$225 pill she needs to take twice a day to shrink a large brain tumor. "This should not be how it's done," Stallman said.

The federal government has proposed ways to reform prior authorization that would require <u>insurance companies</u> to provide more transparency about denials and to speed up their response times. If finalized, those federal changes would be implemented in 2026. But even then, the rules would apply only to some categories of health insurance, including Medicare, Medicare Advantage, and Medicaid plans, but not employer-sponsored health plans. That means roughly half of all Americans wouldn't benefit from the changes.

The 2010 Patient Protection and Affordable Care Act prohibits health insurance plans from denying or canceling coverage to patients due to their preexisting conditions. AHIP, an industry trade group formerly called America's Health Insurance Plans, did not respond to a request for comment.

But some patient advocates and health policy experts question whether insurers are using prior authorization as "a possible loophole" to this prohibition, as a way of denying care to patients with the highest health care costs, explained Kaye Pestaina, a KFF vice president and the codirector of its Program on Patient and Consumer Protections.

"They take in premiums and don't pay claims. That's how they make money," said Linda Peeno, a health care consultant and retired Kentucky physician who was employed as a medical reviewer by Humana in the



1980s and later became a whistleblower. "They just delay and delay and delay until you die. And you're absolutely helpless as a patient."

But there's reason to hope things may get marginally better. Some major insurers are voluntarily revamping their prior authorization rules to ease preapproval mandates for doctors and patients. And many states are passing laws to rein in the use of prior authorization.

"Nobody is saying we should get rid of it entirely," said Todd Askew, senior vice president for advocacy at the American Medical Association, in advance of the group's annual meeting in June. "But it needs to be right-sized, it needs to be simplified, it needs to be less friction between the patient and accessing their benefits."

Customers are increasingly using social media to air their complaints across all industries, and companies are paying attention. Nearly two-thirds of complainants reported receiving some sort of response to their online post, according to the 2023 "National Consumer Rage Survey," conducted by Customer Care Measurement & Consulting in collaboration with Arizona State University.

Some research suggests companies are better off engaging with unhappy customers offline, rather than responding to public social media posts. But many patients and doctors believe venting online is an effective strategy, though it remains unclear how often this tactic works in reversing prior authorization denials.

"It's not even a joke. The fact that that's how we're trying to get these medications is just sad," said Brad Constant, an inflammatory bowel disease specialist who has published research on prior authorization. His work found that prior authorizations are associated with an increased likelihood that children with inflammatory bowel disease will be hospitalized.



Saeed said the day after he posted the picture of the skin rash, the case was marked for a peer-to-peer review, meaning the prior authorization denial would get a closer look by someone at the insurance company with a medical background. Eventually, the biologic medicine Saeed's patient needed was approved.

Stallman, who is insured through her employer, said she and her husband were prepared to pay out of pocket if Blue Cross of Idaho didn't reverse the denial for the drug Zoey needed.

Bret Rumbeck, a spokesperson for the insurer, said Zoey's medication was approved on July 14 after the company consulted an outside specialist and obtained more information from Zoey's doctor.

Stallman posted details about the ordeal online only after the insurer approved the drug, in part, she said, to prevent them from denying the treatment again when it comes up for a 90-day insurance review in October. "The power of the social media has been huge," she said.

Nix had been insured by Blue Cross Blue Shield of Illinois through her husband's employer for almost two decades. Dave Van de Walle, a spokesperson for the company, did not specifically address Nix's case. But in a prepared statement, the company said it provides administrative services for many large employers who design and fund their own health insurance plans.

Nix said an "escalation specialist" from the insurance company reached out after she posted her complaints on social media, but the specialist couldn't help.

Then, in July, after KFF Health News contacted Blue Cross Blue Shield of Illinois, Nix logged in to the insurer's online portal and found that \$36,000 of her outstanding claims had been marked "paid." No one from



the company had contacted her to explain why or what had changed. She also said she was informed by her hospital that the insurer will no longer require her to obtain prior authorization before her infusions, which she restarted in late July.

"I'm thrilled," she said. But "it just should never have happened this way."

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