

CUMMING, Ga.—After three years of doctors' visits and \$40,000 in medical bills didn't cure their daughter's rare condition, April and Justin Beck found a specialist three states away who offered a promising treatment.

They set out before dawn last spring for the nine-hour drive to Arkansas Children's Hospital in Little Rock, where Dr. Aravindhan Veerapandiyan explained how infusions of antibodies could help Emily, now 9 years old, and her misfiring immune system.

They returned home with an appointment to start the infusions. But the Becks' insurer, UnitedHealthcare, declined to pay for a treatment it said wasn't medically necessary.

They decided to fight back. "I really had no idea it was going to be this hard," April Beck said.

Health insurers process more than five billion payment claims annually, federal figures show. About 850 million are denied, according to calculations by appeals company Claimable, based on data from health-policy nonprofit KFF and the Centers for Medicare and Medicaid Services. Less than 1% of patients appeal.

Few people realize how worthwhile those labors can be: Up to three-quarters of claim appeals are granted, studies show.

Patients who fight denied claims must marshal evidence from medical studies, navigate dense paperwork and spend hours on the phone during what is often one of the most difficult times of their lives. They debate insurers over whether a patient might ever recover from a stroke, or whether an expensive new treatment holds real promise.

"Because a lot of people won't appeal, won't call, don't have the knowledge to sit on the phone—a lot of those go away," said Dr. Ezekiel Emanuel, an oncologist and medical ethicist at the University of Pennsylvania.

The sense of futility that keeps people from appealing denied claims is part of a current of anger against insurers that surged in December after the assassination of UnitedHealthcare Chief Executive Officer Brian Thompson.

Insurers say that to remain solvent, they must determine which crises merit reimbursement and which don't. Insurers across categories face similar issues over who and what they'll agree to cover amid rising costs—including home insurance companies that have canceled policies under increasing risks from natural disasters.

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'This appeal saved my life'

Edward Stratton underwent four years of surgeries, radiation and chemotherapy after he was diagnosed with colorectal cancer in 2019. Doctors declared he had no evidence of cancer in July 2023. But the treatments had destroyed his liver.



Edward Stratton and his wife, Darla Stratton, at home in front of a table of medical supplies used to administer his IV antibiotics. PHOTO: WARRIS BOKHARI

Doctors recommended a transplant. His insurer, Elevance Health, rejected the claim and three appeals in letters referencing research showing a new liver didn't improve outcomes for people with colorectal cancer. Elevance didn't respond to messages from Stratton's doctors demonstrating he didn't have cancer anymore.

Stratton, with help from his daughter, appealed again in July 2024 and copied regulators, Elevance board members and journalists on his email. The appeal cited a similar case in which Elevance overturned its denial, and noted two other insurers used updated guidance with more nuanced views of transplantation. Stratton also said denying him a transplant would kill him.

Elevance overturned the denial. His transplant in September was successful. Stratton, who is 65 and lives in Ballwin, Mo., is off disability, back to work as a medical-equipment salesman and playing golf again.

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"This appeal saved my life," he said.

Elevance said in an email that it followed a robust process in reviewing Stratton's case.

"This case, however, involved an exceptionally rare set of circumstances," Elevance said.

In Georgia, April Beck said her daughter, Emily, was an organized kindergartner who loved reading and helping get her classmates in line in 2021. Then she contracted Covid-19 and viral pneumonia. She recovered, but she had changed.

"It was like setting my kid on fire," April said.

Emily woke in the night, moaning and shaking. She couldn't sit still. Her handwriting regressed.

A psychiatrist prescribed Zoloft for Emily's panic attacks and obsessive-compulsive symptoms and guanfacine for ADHD. After a series of tests, a doctor tried antibiotics and an antifungal. Her symptoms subsided. At the start of the 2022 school year, she was thriving.

By November, though, Emily was having frequent meltdowns and panic attacks. Her pediatrician suspected a rare neurological condition brought on by infections, called pediatric acute-onset neuropsychiatric syndrome (PANS) or pediatric acute-onset neuropsychiatric disorders associated with streptococcal infections (PANDAS). The conditions are misfires of the immune system that attack children's brains after an infection.



s and supplements; Emily with her family's young chickens.

Antibiotics and steroids helped quell symptoms. But any cold or cough ignited her more severe behavioral symptoms, too. She kicked and bit, and once tried to jump out of a moving car.

"She's been on antibiotics for two years," April said.

'Mommy cried'

Emily's pediatrician suggested she see a PANS specialist. The closest one was Veerapandiyan at Arkansas Children's Hospital. April spent hours on the phone in the spring of 2024 convincing the hospital to put Emily on his schedule in August.

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Then came the bad news. The hospital said in an email on June 12 that under a new policy it wouldn't take out-of-state patients. The appointment was canceled.

"Mommy cried," Emily said.

April pleaded and got Emily back on the schedule the following week. At that first appointment, Emily regaled Veerapandiyan with all the snake species she could name. Veerapandiyan—known as Dr. Panda to his patients—prescribed immunoglobulin therapy, a solution of antibodies derived from human plasma. In one study of 21 children with moderate to severe PANS published in March 2021 in the *Journal of Child and Adolescent Psychopharmacology*, immunoglobulin therapy improved symptoms by more than 50%.

April felt her prayers had been answered. The family drove back to Georgia with a plan to start the infusions.

The hospital staff sent five prior authorization requests for Emily's treatment through the UnitedHealthcare insurance Justin gets through the construction company where he works as an operations manager. The insurer questioned or rejected each of them.

Veerapandiyan and his colleagues at the hospital traded notes about their efforts to persuade UnitedHealthcare to cover Emily's infusions. Each denial sparked a confusing reconsideration of whether to appeal or submit a new prior authorization request with updated information.



April and Justin Beck read over a denial letter from UnitedHealthcare on Dec. 19.

The Becks hoped Emily could get the infusions closer to their home, but the cheapest provider they could find was more than four hours away and told them the infusions would cost \$36,000 out-of-pocket—far more than they could pay.

In one letter, UnitedHealthcare denied the treatment because the medication wasn't ordered from an in-network pharmacy. In another, on July 25, the insurer said the treatment wasn't medically necessary and hadn't been proven helpful for Emily's condition.

"The services are not eligible for coverage because your plan doesn't cover unproven procedures," the insurer said.

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Rare cases often put patients and insurers in protracted conflict. Some people want experimental treatments that insurers reject because they aren't thoroughly proven to work. But for patients with rare conditions, the number of cases are so small it's difficult to widely document a drug's effects.

Care within two weeks of diagnosis gives PANS patients the best shot at recovery, according to a consortium of doctors who treat the syndrome. Emily had been experiencing symptoms for more than three years.

Emily's family and care providers decided to appeal. It took a month for the hospital to get documents ready to prove that her treatment was necessary and urgent.

April and Veerapandiyan prepared the appeal at the end of August and requested that the insurer get back to them within 72 hours. To qualify for expedited review, patients must prove delaying treatment could jeopardize their life or ability to regain maximum function, or cause severe pain.



home.



's medications for the week.

UnitedHealthcare replied on Sept. 14 that its denial based on the out-of-network pharmacy request was processed correctly and that the appeal wasn't urgent. The Becks and their doctor sent a new appeal to the insurer's escalation unit.

"You have exhausted all levels of internal appeal with UnitedHealthcare," the insurer said in a letter to the Becks on Oct. 30.

New flare-ups

UnitedHealthcare told the Becks that further appeals should go to an independent review organization, a government-contracted group that reviews appeals. A UnitedHealthcare representative later told Veerapandiyan's office that ordering the infusion from an approved pharmacy would require a new prior authorization request. They found a new pharmacy and started over.

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The Becks received a new denial on Nov. 13, saying the treatment wouldn't be covered because it was unproven.

"He could not do anything," Veerapandiyan wrote to the group after failing to persuade a UnitedHealthcare doctor to approve the treatment.

Emily had another flare-up after switching antibiotics. She started wetting the bed. In November, Arkansas Children's Hospital said it had exhausted its options and wouldn't pursue further appeals with UnitedHealthcare.

Emily went from sleeping 12 hours a day to barely sleeping. She flew into fits of rage that she called "her brain telling her bad things." She thought bad guys were coming for her and considered stabbing herself.

Steroids helped relieve the symptoms. "We get these glimpses of her—who she is and who she should be. That's what keeps us fighting," April said.

The Becks paid \$20,000 out-of-pocket in 2023 for Emily's medical care, including occupational therapy, psychiatric appointments, tests, supplements and medications that insurance wouldn't pay for after meeting a large deductible. They accumulated \$6,000 in medical debt. They started a GoFundMe campaign in 2024 to pay for the infusions.

April learned from a Facebook support group for parents of children with PANS/PANDAS about Claimable, which uses artificial intelligence to help patients appeal denials. Claimable was offering to submit claims for PANS/PANDAS patients free of charge.



Emily with her sister, Ava Kate.

The Becks on Dec. 6 sent their appeal to the new denial based on medical necessity by email to UnitedHealthcare, copying Andrew Witty, CEO of its parent company, as well as Georgia's governor and attorney general. Claimable encouraged them to copy Witty on every interaction.

The package included a letter from the PANS Research Consortium stating that immunoglobulin therapy is widely accepted as standard treatment for kids like Emily and that, as of Nov. 22, 2024, 13 states have made it illegal to impede access to the treatment for people with PANS/PANDAS. The letter cited 25 studies backing the treatment's efficacy. It was cosigned by physicians from Stanford and the National Institutes of Health.

The appeal reached UnitedHealthcare's escalation unit and the external agency. April included the half-dozen psychiatric medications they had tried, pictures of Emily's regressed handwriting and four similar cases in which denials were overturned by health insurers.

“It’s on the medical director’s desk,” a UnitedHealthcare representative told her.

HOW TO APPEAL

Five Steps to Take if Your Health-Insurance Claim Is Denied

One day in December, Emily relayed the story of her big trip to Arkansas and showed off the bedroom her sister and grandma decorated for her in a Pokémon theme. She was on the downward slope from a round of steroids and getting over a cold—when symptoms usually start.

April worried about the inevitable flare-up after each new virus or infection. A week later, Emily’s symptoms surfaced again.

Two days before Christmas, a representative from UnitedHealthcare called to say Emily had won her appeal. UnitedHealthcare told the Journal that its medical director decided the infusions would be appropriate as a trial for Emily.

Her parents toasted with prosecco as Emily watched, beaming.

Emily received the first treatment in late January. Each round of two back-to-back infusions took seven hours. Emily’s family and neighbors did their best to distract her with Netflix, visits and toys.

“This has been the battle thus far,” April said. “This could just be the beginning.”

Corrections & Amplifications

About 850 million healthcare claims are denied, according to calculations by appeals company Claimable, based on data from health-policy nonprofit KFF and the Centers for Medicare and Medicaid Services. An earlier version of this article incorrectly attributed the finding to KFF. (Corrected on Feb. 13)

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