Grants Pass Daily Courier

Sunday, September 28th, 2025

Grants Pass resident battles rare conditions, insurance company

By Vickie Aldous of the Daily Courier



JULIE ANDERSON / Daily Courier

Logan Tucker, 20, sits in the backyard of his family's house in Grants Pass. He has wasted away to 108 pounds as he tries to convince an insurance company to cover surgery by a nationally known surgeon who specializes in rare conditions that can cause pain, nausea, vomiting, weight loss and death from starvation.

Grants Pass resident Logan Tucker, 20, is starving to death as he fights a health insurance company's refusal to pay for surgery by a nationally known doctor who specializes in rare medical conditions.

Moda Health has rejected Tucker's first appeal of its refusal, with a decision on his second appeal pending. Legally, he could ask for a review by an independent review organization or file a lawsuit.

But at 5-feet-10-inches tall and only 108 pounds, the former snowboarder and Grants Pass High School soccer player doesn't know how much time he has left. He's been suffering from the rare conditions — which cause severe abdominal pain and vomiting — for more than three years.

He was properly diagnosed this year only after acting as a virtual medical detective on his own case.

"They are in no rush," Tucker said of Moda Health. "I just don't have the time. My body can't stand the pain, vomiting, nausea and being malnourished. I wouldn't wish this on my worst enemy. It's awful."

In a statement this week to the Daily Courier, Moda Health said, "Our top priority is the health and well-being of our members. We have a dedicated team coordinating with him to navigate his care and monitor his progress."

Tucker suffers from a rare condition in which a ligament compresses a major artery — restricting blood flow — and a bundle of nerves deep inside his abdomen, close to his diaphragm. The pressure doubles every time he exhales.

Known as median arcuate ligament syndrome, or MALS, the condition can cause excruciating pain, nausea, vomiting, weight loss and death from malnourishment or starvation.

Surgery to cut the ligament can relieve pressure on the artery and nerves. The operation also involves surgery on the nerves.

As Tucker lost weight and spent years trying to get a correct diagnosis, a second condition developed that is caused by the loss of an internal fat pad — leading to pressure on a kidney vein and section of his intestine.

That condition is called superior mesenteric artery syndrome, or SMAS.

Moda Health doesn't dispute that Tucker has MALS and SMAS, or that surgery meets "medical necessity criteria." The health insurance company has approved the surgery, according to its response to Tucker's first appeal.

However, the company has denied Tucker's request to get the surgeries from California-based Dr. Daniel Shouhed, who specializes in the conditions and uses advanced robotic techniques to minimize complications and the risk of death. The surgeries involve work close to vital blood vessels, nerves and internal organs.

Moda Health said Dr. Shouhed is an out-of-network surgeon and in-network surgeons are available who could do the operations.

Health insurance companies typically negotiate contracts with medical providers to provide care at discounted, negotiated prices — making them in-network providers.

Patients who go to out-of-network providers can face steep out-of-pocket costs.

Tucker said the price of the surgery is $35,000, although that doesn't include other costs, such as a hospital stay during recovery.

In his appeal, Tucker said he's carried out an exhaustive search for an in-network surgeon who can do the MALS and SMAS operations, but keeps striking out.

At least eight doctors aren't actually surgeons. One is no longer accepting new MALS and SMAS patients in order to focus on cancer cases, Tucker said.

An August letter from Dr. Patrick Worth at Oregon Health & Science University to Tucker is typical.

"This letter is to confirm that I have moved to the Division of Surgical Oncology at OHSU and am no longer seeing new patients for median arcuate ligament syndrome or superior mesenteric artery syndrome, as my practice is being focused to oncologic cases only," Dr. Worth wrote.

In rejecting Tucker's appeal of the coverage decision, Moda Health had listed Dr. Worth as an in-network provider "available to provide MALS release and SMAS surgery for you."

It's not uncommon for patients to run into problems finding in-network doctors covered by their health insurance companies. Companies often don't update their lists, or say whether a particular provider is accepting new patients.

Tucker said a local surgeon consulted with his colleagues about whether they could team up to perform the unusual, rare surgeries, but they ultimately decided not to take the risk.

Tucker said he understands the group's reluctance to tackle an unfamiliar operation. Doctors regularly perform complicated surgeries, but the type of surgery he needs is rare.

"They say they don't know enough and don't want to kill you on the operating table," he said.

This week, Tucker said Moda Health has been reaching out to him more, saying it's working to find an in-network surgeon.

He has Moda Health insurance through Asante, where he worked as a phlebotomist before having to stop as his condition worsened. His dad still works for Asante as an intensive care unit nurse.

Tucker said Asante has stepped in to advocate for him, which he thinks is why Moda Health is now showing more interest in finding a qualified in-network surgeon. He's still leery of more delays as the insurance company tries to avoid using Dr. Shouhed, the surgeon he found.

As the fight with the insurance company drags on and the debilitating conditions take their toll, Tucker said he feels like he's running out of time.

He first noticed something was wrong in the summer before his junior year in high school. He would wake up in the morning with a burning stomach, but still try to go to soccer practice.

"I would just throw up at practice. Doctors said, 'Keep trying Tums.' At one point, I was eating more Tums than food," he said.

In 2024, a specialist diagnosed him with functional dyspepsia, a catchall term for a cluster of symptoms including abdominal pain. It can be triggered by anything from stress to excessive white blood cells causing inflammation.

"He put me on antidepressants," Tucker said.

Men with his condition often get misdiagnosed with anxiety, while women are sometimes accused of having eating disorders. Irritable bowel syndrome is another common misdiagnosis, he said.

"I really want to put it out there. Maybe it's not as rare as we think. Maybe they're not being diagnosed," he said.

Tucker also underwent surgery to remove his gallbladder, which again, turned out not to be the cause of his symptoms.

While in a Rogue Community College class studying anatomy this past winter term, he had his first big breakthrough in correctly diagnosing himself.

Tucker saw an image of a cluster of nerves in the upper abdomen.

"I was like, 'That's where my pain is,'" he recalled.

Another breakthrough came when Tucker requested more medical imaging. The results were interpreted as normal, but he requested a copy himself, took a close look in June and noticed a red flag involving a blood vessel. That led to the SMAS diagnosis, and later the MALS diagnosis.

For such a young person, Tucker has an extensive knowledge of the medical field. He started work as a phlebotomist, which involves drawing patients' blood, while still a teen. Both his work and education are on pause for now.

Tucker said he started passing out at work from being so malnourished. His illness also interfered with his ability to help patients.

"I would run out of the room to throw up. It's hard being the health care worker when you should be the patient," he said.

With the surgeries, Tucker hopes to regain his health, continue his education and someday become a doctor.

"My goal is to be a pain specialist doctor because I know what it's like. I want to be the doctor that I didn't have," he said.

Tucker said people see how skinny he is, but don't know he's spent years suffering, hoping to find a treatment that works.

"People meet me and say, 'You need to eat a burger.' I'm waiting for that. I want to," said Tucker, who mainly subsists on juice and vitamins.

Having just turned 20 years old in August, Tucker is missing out on many of the experiences enjoyed by teens and young adults. He's grown too weak to leave his family's house in Grants Pass to hang out with friends.

"I can't do anything fun. I can't eat. I didn't notice before how much people go out to eat," he said. "You don't understand how good it is and how privileged you are until you can't do it. I've definitely gained respect for what I have in life."

To help deal with medical bills and lost work income, Tucker has a GoFundMe fundraising site at gofund.me/21f90c96.

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