PR

PATIENTS RISING

RECONCILIATION 2025

"OUR SON IS AN EXAMPLE OF HOW THE SYSTEM SHOULD WORK."

THE WAIT THAT COSTS TOO MUCH

LONG DELAYS, LIMITED PROVIDER ACCESS UNDER MEDICAID QUIETLY RESHAPE PATIENT OUTCOMES

THE WAIT, THE FLIGHT, THE CALL THAT CHANGED EVERYTHING

Latasha's youngest daughter lives with adrenal insufficiency and epilepsy, two rare conditions that require constant vigilance and have led to multiple emergency room visits, ICU stays, ambulance rides and even a medical flight.

"Especially the past six months, we've had a flight and four ambulance rides and three or four ICU stays … probably six ER visits," she said.

After an initial denial, Latasha joined Patients Rising's We The Patients Hill Day to advocate for families like hers. The next afternoon, she received official word from the state: her daughter had been approved for disability services and Medicaid. "I cannot tell you, I'm in awe how much that helps our family," she said. "It costs so much to just survive, right? So we're so thankful."

The coverage may be retroactive, potentially offsetting significant out-of-pocket costs. "Whatever my insurance didn't cover — it's a lot of bills — it will go back and hopefully cover that," she said. "I was able to call the ambulance folks and the hospital … they were able to enter in her information that she's covered."

Her daughter's medication regimen was recently improved, reducing her daily pill burden and easing side effects, and a GI referral is underway to explore whether poor absorption is affecting treatment. "That really helped … just her stomach and being able to take all that medication," she said.

Latasha is also hopeful about a wearable cortisol-monitoring device under development. "There's announcements of a monitor that maybe can check for cortisol," she said. "That would be amazing."

With school on the horizon, Latasha is working closely with her daughter's team to transition from homebound instruction and prepare for the fall. "My hope is that we can start school normal, you know, whatever normal is," she said. "We have all these new things that have happened. Things have really changed for us in the past six months."

This next chapter is uncertain, but it comes with something they haven't had in a while: options.

MEDICAID FINALLY SAID YES. BUT THE DAMAGE WAS DONE.

“If I didn’t have to wait to be approved by Medicaid, I would have saved my fingertips and my right toes.”

Kimberly Gonzalez was diagnosed with scleroderma and Raynaud’s at just 12 years old. These autoimmune conditions restrict blood flow and cause tissue damage. The longer treatment is delayed, the more permanent the consequences. By the time Medicaid approved her coverage, it was too late to reverse what she had already lost.

Her family did everything they could to keep her stable in the meantime. They paid out of pocket for appointments, medications and early interventions, even as the bills piled up. Eventually, those costs forced a choice no family should have to make.

They lost their home trying to keep their daughter alive.

“I didn’t know at the time,” Kimberly said. “My parents never talked about money. But waiting on my Medicaid approval is why we lost our house.”

Even now, Medicaid doesn’t guarantee access. When her doctor prescribes a medication, she’s often given a lower-tier alternative with more side effects.

And when she needs a specialist, finding one in-network is rare. “The hardest part isn’t the paperwork,” she said.

“It’s getting treatments approved on time and finding doctors in my network.”

She also needed a bone graft to save a bottom front tooth, a $4,000 to $5,000 procedure Medicaid wouldn’t cover.

It was only possible because her younger sister offered to pay half. “It’s not about how I look,” Kimberly said. “It’s about being able to eat.”

She was 15 when Medicaid finally kicked in. By then, the damage had already been done, affecting not only her health but also her family’s stability.

Medicaid is supposed to prevent this kind of fallout. But when approval drags and coverage excludes what patients actually need, families like Kimberly’s are left to absorb the full cost physically, financially and permanently.

WHEN A SAFETY NET BECOMES A TRAPDOOR

“I was removed from Medicaid without cause and left to prove my own existence in federal court.”

In 2016, Ian Scheil began experiencing tremors. What initially appeared as benign muscle twitches soon revealed a deeper neuromuscular disorder that altered the course of his life. Muscle weakness, stronger tremors and increased instability followed. Medicaid allowed him to access care that kept him functioning.

But then it vanished.

Without medical justification, Ian’s Medicaid coverage was terminated. The Social Security Disability Administration removed him from eligibility, not because of improvement, but a bureaucratic error. It was an administrative mistake that resulted in a personal fallout.

Ian did not accept the decision. He took his case to federal court and proved to be relentless in his advocacy. He constructed his own defense, navigated a system built to exhaust, and challenged the presumption that patients must constantly re-qualify for conditions that do not resolve.

His case was an indictment of a system that prioritizes paperwork over medical reality.

And get this – He won. His benefits were reinstated, but the damage done during the gap. He went months without coverage, experienced interrupted care and stalled his clinical progress

You can’s really put a price on that.

Ian’s case illustrates what happens when oversight becomes obstruction. It raises questions about eligibility redetermination practices and the structural precocity of Medicaid coverage for individuals with complex medical needs. His diagnosis did not disappear, and yet the burden of proof fell entirely on him.

What his story reveals is this: Medicaid is only as stable as the systems that manage it. When coverage becomes conditional on administrative consistency, patients are forced to fight for more than their illness.

SHE WAS DENIED, DISMISSED BUT STILL MOVED FORWARD

Scleroderma doesn't knock. It slides in under the skin, tightens the grip around the fingers, slows the breath and waits.

When it arrived for Demeshia Montgomery, she was 19 and unaware that a diagnosis could feel more like a sentence than an answer.

Her hands were the first to change. They turned cold in rooms that were warm. They ached in silence. They split open at the fingertips, as if rejecting the very idea of touch.

Scleroderma is a chronic autoimmune disease that causes the body to produce too much collagen, leading to the thickening and hardening of the skin and, in more severe forms, internal organs. It can restrict. movement, damage blood vessels and impair lung, heart and kidney function over time.

While symptoms vary, they often begin with Raynaud's phenomenon, which is a circulatory issue that makes the fingers and toes turn white or blue in response to cold or stress, and it eventually and progress to painful ulcers, joint stiffness and fibrosis.

There is no cure, and treatment focuses on managing symptoms, slowing progression and preserving quality of life.

Demeshia, or Deme as her friends call her, didn't receive access to Medicaid until she was 25, and only after she was approved for social security disability in the state of Ohio.

You would think that would have brought her relief; however, it only created a new phase of waiting.

She was assigned a case manager, granted transportation assistance and referred for occupational therapy, all in a single sweep of approvals that felt, for a brief moment, like momentum. The sessions gave her something tangible to hold onto. She was granted six hours a week in therapy, but sessions were slowly reduced until Medicaid stopped approving her time.

No explanation was provided.

Deme was also measured for stints that would have kept her fingers extended and functional. They would have slowed the inevitable curling caused by scar tissue and loss of elasticity, but the stints were denied without reason when they would have been her best chance at preserving their shape and functionality.

Over time, the denials became a pattern. Deme learned that with Medicaid, being approved was not the same as being supported.

She began to encounter the full weight of step therapy, which requires individuals to first attempt and fail on lower-tier medications before receiving access to the drugs their physicians had carefully selected. Her doctors provided detailed records, submitted justification, and appealed with clinical precision, yet the system remained unmoved, prioritizing procedure over judgment, and budget over biology. The treatments she was forced to try had already proven ineffective for others with her condition, and there was no medical reason to expect a different result. Still, she was required to comply.

Specialist care, though essential, proved equally fragile. In her region, rheumatologists, pulmonologists and nephrologists were already in short supply, and those who accepted Medicaid were often unable or unwilling to take on complex cases like hers. Some declined outright, citing limited capacity or lack of familiarity with scleroderma. Others reviewed her records and simply said no.

She was told more than once that her condition was too advanced, too unpredictable, too resource-intensive to manage within their current patient load. The refusal was rarely framed as personal, but its consequences were. At one point, she had access to only two rheumatologists within driving distance, and those providers could disappear from her network at any moment, either by shifting policies or changing practice locations, leaving her without care and without recourse.

For Deme, the struggle was never limited to the disease alone. It was the infrastructure wrapped around it, the policies written without her in mind, and the care that arrived too late or not at all. She had learned to live inside the layers of scleroderma, its tightening, its unpredictability, its toll on her lungs, her hands, her heart, but she had also learned to live inside the bureaucracy that managed her care with distance and delay.

HE DIED WITH INSURANCE

BUT HE STILL DIDN'T HAVE ACCESS.

"He died because of poverty. It was not the only factor, but it shaped the trajectory of everything that followed."

Liz DeWeese and her husband, Don, had advanced degrees, a shared calling to ministry and a long history of serving congregations during periods of transition. Their work was meaningful, but it came without financial security. When his health began to deteriorate from long-standing diabetes, their lives narrowed into a daily calculus of risk, delay and adaptation.

They were covered by Medicaid at the time of his death, and was both the reason he had access to care at all and the reason that care came too late. For years, Don had rationed insulin. Liz suspected it, but could not confirm what she could not afford to fix. When he was eventually evaluated for bypass surgery, the vascular damage had already advanced. Foot wounds became routine, and neuropathy had dulled his ability to recognize injury.

A podiatrist recommended amputating several toes, but a vascular surgeon later reviewed his case and determined there was insufficient circulation to support healing. The only viable option was a below-the-knee amputation.

He entered acute rehabilitation and made significant progress. For a time, he appeared determined to begin again. But on the eve of his discharge, he was readmitted to the hospital with signs of congestive heart failure.

At that time, they traveled for job interviews with physician approval, but burning that trip, he contracted COVID. And though his respiratory symptoms remained manageable,

the virus triggered C. diff, and further complications followed.

Don cycled in and out of skilled nursing facilities. Medicaid covered the cost, but the conditions stripped him of any remaining sense of autonomy.

When coverage ran out, Liz was left with two options: place him in long-term care or bring him home. She brought him home.

Don died in the front seat of the family car one day before the move to what they believed would be a new chapter.

During those final months, Liz was parenting two pre-teens. Their extended family was several states away. She was managing the logistics of care, housing and grief without support. Medicaid allowed them to survive, but it did not offer stability. And when care was available, it was often undermined by delays, poor coordination or institutional neglect.

Her husband's decline was not caused by a single failure. It was the result of years spent navigating a fragmented system where eligibility did not guarantee access and coverage came tethered to constraints. The cost of care was measured not only in dollars, but in hours, dignity and irreversible damage.

Medicaid is meant to offer protection. Liz's story reveals what happens when that protection arrives piecemeal, when it cannot outrun the consequences of delay, and when the system designed to safeguard the vulnerable leaves entire families carrying the weight of what it cannot provide.

CARE THAT EXISTS ON PAPER. NOT IN PRACTICE.

Katie Moureau's daughter, Cade, lives with Prader-Willi Syndrome, a rare genetic disorder that requires continuous and highly specialized care. Cade sees multiple providers, needs tailored medications and depends on consistent insurance coverage. Medicaid was meant to help fill the gaps, but instead, it introduced a new layer of barriers.

"The hardest part isn't the paperwork," Katie said. "It's finding doctors who understand her condition and are actually in-network."

Their family has strong primary insurance, which helped shield them from the most severe delays. Still, Medicaid was supposed to enhance Cade's access to care, not complicate it. Even after approval, Katie found herself constantly advocating, appealing and negotiating for services that had already been deemed medically necessary.

"You expect that once you're approved, care will be straightforward," she said, "but it isn't. You're always in a position to prove your child deserves the care the system has already agreed to cover."

Prescription access has also become unnecessarily complicated. Pharmacies that accept their private plan often don't accept Medicaid, and finding one that works with both requires time and persistence that most families simply don't have.

Now, with a new pharmacy benefit manager controlling access to medications, Katie is facing yet another obstacle. Formularies change without warning, authorizations are delayed, and the system has no real process for accommodating children with rare, high-need conditions.

Medicaid was never meant to be the obstacle. For families like Katie's, it was supposed to provide stability and support. Instead, it has become one more system to manage — one that demands time, expertise and relentless follow-up just to get the basics.

Cade's condition may be rare, but the problems surrounding her care are not. Her story shows how even the best coverage can fall short when coordination breaks down, delays mount and the structure meant to help becomes yet another burden to carry.

WHEN SERVICES CONNECT TO REAL LIFE, FAMILIES CAN THRIVE

When Jennifer Garzia's son was born, the differences were noticeable almost immediately. His muscles lacked tone, his movements were minimal and feeding didn't come naturally. He was quiet in a way that felt clinical rather than calm.

These early signs brought him into the NICU, where he was evaluated by a geneticist and underwent targeted testing. Within 30 days, he was diagnosed with Prader-Willi syndrome, a rare genetic disorder caused by the lack of expression of certain genes on chromosome 15. The diagnosis offered clarity, but it also marked the beginning of a long and complicated relationship with the systems responsible for his care.

Prader-Willi syndrome affects the hypothalamus, disrupting the body's ability to regulate hunger, hormones and temperature. Children with PWS often experience delayed milestones, cognitive challenges and behavioral rigidity, and many develop an intense drive to eat that requires constant supervision.

The condition is lifelong and demands coordinated care across medical, nutritional and educational settings.

In the early years, access to care came more easily. The Garzia family lived in Pennsylvania, where Rocco qualified for Medicaid based on his disability. That coverage allowed for timely therapies, regular evaluations and support that aligned with his diagnosis rather than his family's income. For a condition as complex and multifaceted as PWS, that early access helped stabilize what could have easily spiraled into crisis.

As Rocco grew, new challenges emerged. His behaviors became harder to manage, especially within school settings that were not equipped to respond appropriately. He was enrolled in a special needs program, but the school's approach emphasized compliance over understanding. Restraints were used routinely, and seclusion replaced support. In one incident, Rocco was held down to the point of respiratory distress, so Jennifer pulled him out of the

classroom. She could no longer trust the environment designed to educate him.

The family moved to Florida hoping for a fresh start. Instead, they encountered a system governed by different rules.

In Florida, Medicaid was income-based, and disability status no longer guaranteed access. Jennifer submitted documentation, made phone calls, asked questions and received little in return. The same diagnosis that had once qualified her son for coverage now triggered a bureaucratic impasse.

“When I explained what happened in the school, that’s when they finally called it a crisis. That’s the keyword. And only then did we get the Medicaid waiver.”

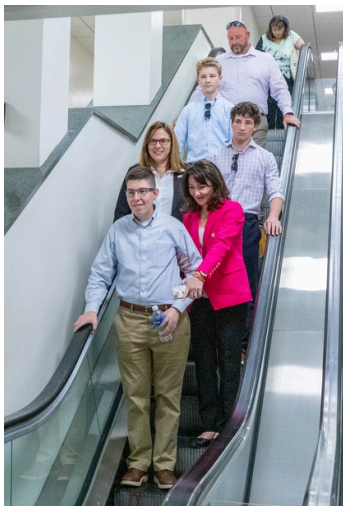
That one word made all the difference. It unlocked the services Rocco had needed.

Jennifer is unequivocally grateful for the waiver, but the process left its mark. “Even with good caseworkers, the process is exhausting. Your nerves are shot. You’re scared. You’re trying to figure out how to pay for something while waiting for the system to catch up.”

And she doesn’t take the support they’ve received for granted. Jennifer’s aware of the families still stuck in limbo.

“I believe Rocco’s journey is meant to shed light on what needs to be reworked, and he’s an example of how a program can support someone with complex needs.”

Jennifer stays hopeful, but continues to ask the bigger question: What can we do for the most vulnerable before they fall through the cracks?



COVERAGE CHANGED HER LIFE. GETTING IT NEARLY COST HER

Amanda Gershon lost her insurance at nineteen. She had been in college, balancing coursework and planning for what came next, when a sudden health crisis forced her to withdraw. With her enrollment went her coverage, and what followed was not a sharp collapse, but a quiet unraveling that stretched over a decade.

"It was an uninsured spiral," she said, "from age 19 to 32." During that time, she managed the best she could. She worked two jobs, paid for prescriptions out of pocket and endured the reality of being sick in a system that offered no safety net. "Working two jobs sick, that's all I could do."

Her condition worsened as the years went on. She watched her health decline while access remained out of reach. "If I didn't have to wait for Medicaid, if I could have gotten it before disability, I believe I'd still be working," she said. "My health got worse and I couldn't do anything about it." When Medicaid finally arrived, the timing offered access, but not rescue. "I nearly died at 33 years old waiting for appointments after I finally got Medicaid as a disabled person."

She still remembers what it felt like when her coverage was approved. "I cried several times, including picking up my prescriptions." For Amanda, Medicaid brought the start of a return, but it did not come quickly or cleanly. "It was a difficult first few years picking through the mess my body was allowed to decline to, a point that was a very difficult fight back to function."

By 2019, she thought she had reached a place of balance. Her health had stabilized, and she felt in control again. "I thought I'd gotten my health to a manageable point finally," she said, "but had a random heart attack at 36." It wasn't her first warning. At 33, she had been told she had six months to live. Still, she pushed forward. "I refuse to give up yet," she said. "We're all going to die, but I'm not ready, and with healthcare I am able to fight back."

Medicaid shifted the trajectory of her treatment plan. "Uninsured, I had to ignore my mental health until Medicaid. I've been able to reach the point of loving myself, self-esteem, and learning to balance my life better." With consistent care, she turned her focus outward. "I'm more proud of my life on disability doing social justice advocating and community leader within my city. I'm known as a help to everyone."

Still, she knows that the system demands effort even from those it's supposed to support. "The hardest part of Medicaid is truly the renewals," she said. Despite being on SSDI, she has had to fight to remain enrolled. "DHHS is so far behind. In November I had to go in person to force the renewal to get done. Now my state wants to do it more often." The irony is not lost on her. "They get my information from Social Security itself," She said. "They have access to my bank accounts." And yet she is made to resubmit, reprove and repeat.

Amanda speaks from lived experience, not theory. Her survival is not framed by triumph, but by clarity. "What Medicaid has done for me is give me a much longer life and a much better quality."

PATIENTS RISING

Empowering every patient in America to advocate for reforms placing them, alongside their doctors, in control of their healthcare choices.

www.patientsrising.org