Iowa mom turns to geneticist to solve family's medical mystery

Determination drove Viles to uncover rare condition

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Des Moines Register
USA TODAY NETWORK

Jill Viles has a picnic with her husband, Jeremy, and her son, Martin, at Spring Lake Park in 2017. Viles died in June 2025.
ZACH BOYDEN-HOLMES/DES MOINES REGISTER FILE

DES MOINES – Jill Viles needed to scream.

Don't yip, her father encouraged. Not the twerpy chirps that betrayed her nickname, Pip Squeak. *Roar*, from the diaphragm, operatic, like a diva straining to reach not the last row but the passersby on the street outside the theater. Maria Callas shaking her fists at the heavens.

This cacophony had a point. The yelling was a lesson in protection between father and eldest daughter, who shared a condition that had lingered like a spongy moth in their family tree for generations, defoliating some branches and leaving others to flower.

Viles was skin and bones, but naturally. Her muscles were wasted in her extremities and her joints were constricted at critical junctures, permanently rendering her into a Barbie doll position: elbows cocked in a near 90-degree angle, jaw raised and heels elevated, as though she were wearing invisible stilettos all the time.

Her gait was unsteady, like a colt that hadn't mastered its hooves. And inside her chest, her heart beat like a malfunctioning metronome, sometimes spasming off-rhythm.

Her father, Robert Dopf, a prominent federal prosecutor, was similarly built. Except that he had "Popeye arms," as Viles called his thin biceps and huge forearms, whereas she was small all over.

As a young man, he'd wanted to be a fighter pilot, even got a nomination to the Air Force Academy. But the stiffness in his tendons meant he walked on his toes, couldn't force his heels to the ground despite every effort. He failed a physical, and a second one, too.

He relented on that dream, but not much else. He had a disability, but he was going to do *more*, be *more*, live *more*. He never gave in, said his wife, Mary Dopf, and he wouldn't let their daughter give in either.

He knew that in the face of danger, Viles couldn't run or kick or jab. But she could scream.

"I had just one weapon in my arsenal – my voice – and he needed me to fine-tune this asset, wield it like a weapon," Viles wrote of the moment in her recently released memoir, "Manufacturing my Miracle."

Viles would come to learn that her voice could be many things, not just a cudgel – a realization cataloged many times in a slew of interviews, dozens of her blog posts and one popular episode of the radio show "This American Life."

Her voice could be a whisper when needed, like in the stories she told herself as a brainy child grasping fiction to make sense of her difference.

It could be the clank of divining rods, diagnosing – despite decades of doctors' fruitless exams – not one but two diseases plaguing her family. And, later, identifying one of those conditions in an Olympic hurdler she'd never met using just Google images and gut intuition.

It could be a siren, forcing the medical establishment to listen – co-authoring two major scientific papers and saving at least three lives. Or a megaphone amplifying the rights of patients to be investigators in their own health. Or a herald, ushering in life-changing revelations, including a way, possibly, to finally put right the genetic error that stole her mobility.

Or it could spill out in ink instead of in sound, over pages where she could reckon with the disease – the one her family didn't speak about, whether from denial or fear or the Midwestern tendency to keep your chin up.

Don't dwell, her sister, Janet Albanese, recalled was the de facto family motto. *You're going to have a great life. And this doesn't have to be your identity.*

But it could be. Partly, at least. Viles could use her voice to reclaim her story from doctors, from textbooks, from people who saw her limbs and scooter and thought she was weak.

And maybe in raising her voice, she could show others the power of believing in theirs, too.

Deciphering reality through stories

When the principal called Mary Dopf early in her daughter's kindergarten year, she was sure he wanted to talk about the tripping. Viles' falls had become violent; not losing her footing like other kids, but like her legs were swept from under her. Just brutal collapses, Dopf said.

Instead, the principal asked her to visit the classroom. *Look,* he said, gesturing: While other kids awkwardly traced letters, Viles sat nose-deep in "Charlotte's Web."

A chapter book, the principal emphasized.

The story of a wise and kind spider named Charlotte who saves her friend, Wilbur the pig – the runt of the litter, which immediately hooked the diminutive Viles – by weaving words into her web. The oddity and spectacle, Charlotte figured, would certainly save him.

The fatefulness in Viles' choice of *that* chapter book, Dopf said, would take decades to see clearly.

Viles eventually grew into a chatterbox who didn't know a stranger. But, as a child, she was introverted. Not shy, per se, but bookish and observant, content to be lost in deep rumination.

Born in 1974, Viles had an innate fastidiousness. As a grade schooler, she compiled a card catalog for the family's book collection – for fun. When Viles and her siblings, a brood that grew to five, played Dopf Apartments, pretending the rooms of their house were units, Viles was always the manager, keeping the "renters" abreast of the rules in the lease.

Viles liked writing – storytelling, really – going back as far as her mom and sister can remember. She filled notebooks with stories – "Mr. Ranger's Good Ideas" was her first title – and took lead on writing a local newsletter, the Caring Neighborhood Association, which her siblings sold for a nickel door to door.

So when the falls started, Viles told her mother she was being plagued by "witches' fingers," unseen tendrils that came from below to wrap around her legs or arms and wrench her to her knees or into her bike handlebars or *splat* onto her face.

What was happening to her physically was uncanny, phantom even – like she was always one toe away from a set trap, but she could never see the trip wire. She'd check out library books on the occult and possessions and ghosts. She wanted to probe supernatural experiences because she, too, was prey to invisible forces. And she had an imaginary friend, Murphy, who broke his legs or was in a wheelchair.

"She was trying to figure out her own legs," said Albanese, Viles' sister. "She knew something wasn't right, and even as a little child, it was her way of trying to understand something's different."

The family "wore out the road" between Des Moines and the Mayo Clinic during much of the 1970s and '80s, Dopf said. Viles, the oldest sibling, endured the most time in clinics and operating rooms. The parents believed the invasive tests and procedures were helping researchers find a cure – or a salve, maybe. An answer, at least, to what had burrowed into their family tree.

"The sad thing was nobody was working on it," Dopf said. "I think that's where Jill felt like she had to take things into her own hands and seek out the people that were doing something specifically with this muscular dystrophy."

Even as Viles was struggling with worsening symptoms, leapfrogging her father in the disease's severity, Dopf said, "her spirit was so strong."

Most days, Viles' default attitude was sweet, a complement to her soft feminine look. But righteous defiance always stood in its shadow. Like when she spewed pink liquid over a snotty nurse's whites for being too rough, or when she hissed "I hate you" to the smug photographer taking a "before" photo of her extreme scoliosis. Her forced positioning, her nakedness, was an immodesty almost too much to bear.

The photo was the kind used in textbooks, she knew, her eyes sure to be covered by a black bar. Anonymous. Was that to guard patient privacy, Viles wondered in her book, "or to shield the medical community from the humanity before them"?

As Viles graduated high school, finding the answer to her family's medical mystery seemed a necessary key to unlocking the goals she'd long journaled about: namely, having a child.

By then, she'd stopped accepting shrugs and half-measures. Defining what had gone so "haywire" in her body, she wrote, had become "a matter of human dignity."

Viles finds an answer – but will anyone believe her?

When Viles started at Drake University with the aim of studying genetics, she stood a little over 5 feet and weighed less than 100 pounds: a child's amount of muscle, and nearly no fat, on an adult frame.

With access to a research library, she took up residence in its stacks during her freshman year. She riffled through the "muscle disease" sections in textbooks and scientific journals, trying to pair her particular symptoms with a diagnosis.

Nothing in this article, so on to the next. And the next. And the next. Day after day. For months.

Until the flip of a page prompted her to stop short.

The man in the photo had her dad's "Popeye" arms: thin bicep, huge forearm. The text said they were a hallmark of an ultrarare disease: Emery-Dreifuss muscular dystrophy.

Viles ticked through traits: Arms bent at the elbow? *Yes*. Heels that float off the ground? *Uh-huh*. Chin perpetually unable to touch chest? *Check*.

But the report also mentioned cardiac issues, serious ones – concerns that seemed much graver than they'd ever considered the flutters in their chests.

When Viles' dad stumbled across her research in a pile of papers on the kitchen table a few weeks later, he went ashen. He told his daughters that doctors had always assured him his heart conditions had nothing to do with his muscle disease.

They do, she insisted, as sure they had Emery-Dreifuss as that the sun would set that night. *And you need to be seen by a cardiologist*.

Viles' called the local heart clinic to make an appointment – and called, and called, and called, until the nurse finally put her father on the schedule. The tests they ran produced such worrying results, including a lethally slow pulse, that her dad had a pacemaker installed before the week's end.

In her family's telling of the story, this marked the first life Viles saved. Her father's.

But even in the face of her dad's experience, neurologists didn't put faith in Viles' diagnosis. Some wouldn't even entertain it. A teenager who had seen lookalike photos in a journal? A stretch in the best of times. And, to give them a bit of grace, Emery-Dreifuss was thought to be a male-only disease.

"I remember a doctor just stared at her and said, 'You're wrong, you're wrong, you're wrong,' " Mary Dopf said. "But 'relentless' is a word for Jill."

She adopted the mindset of constant movement, Albanese said. *Forward is a pace*.

"She said: I'm going to move where I see things that haven't been explored or discovered. I'm not going to put the idea out there for somebody else to do, I'm going to figure out how to do it," Albanese said. "And she knew she had the smarts."

Viles' days in the reference department led her to a group of Italian scientists studying Emery-Dreifuss in hopes of identifying the gene mutation that caused the disorder. She put together a packet of information for the researchers, replete with family history. By then, the family knew that four of the Dopf children had inherited their father's condition, though only two had severe cases: Viles and her brother, Aaron, who were born on the same day exactly four years apart. "Soul twins," as Dopf called them, who shared a special connection, given their circumstances.

Viles decided to send the researchers photos. That's how she identified the disease in her family members, she figured. And visibility, as she learned in her kindergarten favorite, "Charlotte's Web," created interest. So she stripped down to her underwear and set the timer on her camera. Immodesty was replaced with brazenness when on her own terms.

She'd ship them blood, too, after cajoling a friend into snatching a few needles and vials from the hospital where she worked.

Nearly four years later – just before the turn of the new millennium and prior to the human genome being fully mapped – Viles heard that the diagnosis was confirmed.

The family had Emery-Dreifuss muscular dystrophy, the result of a rare mutation on the Lamin gene.

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