

How medicine erased Black women from a ‘white man’s disease’

By Eric Boodman

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Cristi Taylor-Gentry (second from right) and her twin sister Christa in their elementary school Blue Birds group in Tulsa, Okla.

PHOTO: COURTESY CHRISTI TAYLOR-GENTRY

What Christi Taylor-Gentry remembers most about third grade are the times when the teaching stopped and she and her twin sister were sent out of the room. They were new at Lanier Elementary. Their parents were newly divorced, their mom living in a subdivision on the northwestern edge of Tulsa, Okla., with manmade ponds and curvy sidewalk-less streets.

It was the 1970s — two decades after *Brown v. Board of Education*, but Tulsa schools had only just been dragged toward desegregation. Taylor-Gentry’s parents chose Lanier, on the south side: A school in the white part of town, they figured, would have more to put into their kids’ education. Every morning, before the 20-minute drive, she and her sister would wake at 5, submit to their mom’s vociferous combing or get a light comb-clunk on the head.

They were the only Black students there. They made friends, became Blue Birds, wore the uniform of red vests over white shirts, with navy skirts and knee socks. That year, “*Roots*” came out on ABC, and a classmate took to calling her Toby, the name the slave owner gives the main character in the miniseries. Every so often, a kid would use the N-word within earshot of a teacher, and the class would grind to a halt. There would be a Conversation, while Taylor-Gentry and her sister were sent to help out with the

kindergartners, or get such-and-such from the teachers' room, or go read in the library. She loved Mrs. Piggie-Wiggle, how Hubert who wouldn't pick up his toys ended up barricaded in and had to receive dinner through his window, on the tines of a garden rake.

She came from a family of teachers — generations of them, and she became one, too, in Ohio, where she'd gone to college. But then, when she was about 40, joint pain started getting in the way. It had started with her knees and lower back in her 20s. Now, the throbbing in her elbow would wake her up in the wee hours, as if she'd somehow broken it in her sleep. Some days it was hard to move. One doctor dismissed it as a quirk of heredity. Another said [fibromyalgia](#), and put her on meds that didn't help. A psychiatrist told her she just had to push through: Just do it, like the Nike ad said.

Eventually, she found herself in a rheumatologist's office in Columbus, her joints being painfully pulled at and swiveled. After, as the doctor helped her down off the exam table, he said he was pretty sure this was ankylosing spondylitis. He wrote it down for her, so she could look it up. It was typically found in white men, he went on; he didn't think there could be many more than 20 Black women in America who had it.

Taylor-Gentry was shocked. He was a good doctor — one of the best she'd seen: kind, thorough, probing issues others hadn't taken seriously. But did she actually have this disease? When she looked it up, there was almost nothing about Black women in the scientific papers she found. Was she really such a rarity? It wasn't a good feeling, this strange sense of being alone. There was something familiar about it, like walking into a room you recognize but can't quite place.

A self-replicating hypothesis

Even for a “stereotypical” patient, ankylosing spondylitis can take years to get diagnosed. If, like Taylor-Gentry, you're seen as an anomaly, the delay can be even more extreme. For Wendy Covington, it took a decade. It started in her knees, as if some crucial piece were being wrenched out of place. She called her mom, who lives near her in North Carolina. “I said, ‘Can you please bring me the walker that Uncle Eddie's mother-in-law was using? I need it. I can't walk.’” Uncle Eddie's mother-in-law had been in her 90s; Covington was 28. In the hospital, the pain faded with steroids. But there was no diagnosis. When friends called, worried, asking what was wrong, she wasn't sure what to say. “None of the doctors knew what this was,” she said.

For Roz Tolliver, of Merced, Calif., it took 30 years. Her dad had had AS, his vertebrae totally fused. He couldn't lift his chin away from his chest. He'd grown up a sharecropper, lied about his age to enlist in World War II “to get the hell out of

Mississippi.” He wasn’t one to complain. Only after his death, when she got her dad’s records from the VA, did she realize her many unexplained symptoms mirrored his. She told her doctors. “They just dismissed it,” she said.



It took Wendy Covington a decade to receive an ankylosing spondylitis diagnosis.
JAY HARRISON

It wasn’t the only thing they dismissed. There was the throbbing in her pelvic bone, which her pain management physician didn’t believe in until she happened to land in the ER for something else. By chance, a scan revealed an issue in the cartilage of her pubic arch. “I took it to my doctor, and I showed him; that’s when he looked at me, and he’s like, ‘Oh, wow, you do have pain there.’ It’s so insulting,” she said. Same thing with her shoulder. “I just feel like as a Black woman, I am not taken seriously. Until the evidence is in front — this objective evidence — I am not to be believed.”

That pattern of dismissal is well-documented and widespread. But in ankylosing spondylitis, it’s uniquely ingrained. “When people were in medical school — even when I was in medical school — it was taught that this one specific disorder, it really happens in this particular patient population,” said rheumatologist Alexis Ogdie, director of the University of Pennsylvania’s spondyloarthritis program. She got her M.D. in 2006. What was the snapshot her professors gave? “A white young man’s disease.”

AS sits in a kind of thorny tangle, where biological mystery, gender discrimination, sex differences, racism, and genetics meet. It's hardly the only "white disease" (a label pasted onto both [cystic fibrosis](#) and [multiple sclerosis](#)). Nor is it the only one where women run a greater risk of being misdiagnosed (look no farther than the humble [heart attack](#)). It probably isn't alone in having the dubious distinction of being both: These forces, after all, lurk in seemingly every corner of medicine. What sets AS apart is the way patients have begun naming the misogyny and the misuse of race that's shaped their illness, untangling how it came to be. Even as science shifts, they've seen, old clinical habits of mind remain, which can in turn affect the science.

Classically, it was known as a disease of inflammation and excessive bone growth in the spine. Now, it's understood to be part of a spectrum, one form of spondyloarthritis among many, symptoms sometimes overlapping, gut issues coinciding with knee issues, heel pain presaged by psoriatic [rashes](#). When rheumatologists were demarcating AS, though, they created strict borders, a disease defined by how it looked in men. Its prevalence was also reported to vary. Rarer in Japanese people than in Chinese, the literature [said](#); more common among Northern Europeans and certain Native American groups, very rare in those of sub-Saharan African descent. Unsurprisingly, the categories are often translated into race.

But race is an [unreliable proxy](#) for the complex interplay of genetic probabilities that might lie in someone's family's past. Take [Dawn Gibson](#), a health writer and patient advocate living with AS outside Detroit. "I am what's called part of the Loving Generation. My mother is white, my father is Black. They were allowed to marry because of the Supreme Court decision [Loving v. Virginia](#)," she said. Her father's genome likely bore traces of white rape during slavery. She identifies as Black, and American society reads her as such. As she put it, "If you see me walking down the street, you would never know how much European ancestry I have."

"He told me that he wasn't going to look at anything any further than any of the other doctors, that there's no way that anything else could be wrong with me."

MINIONETTE WILSON, AS PATIENT AND ADMINISTRATIVE ASSISTANT
AT DUKE UNIVERSITY SCHOOL OF MEDICINE

Gibson sees it as a self-replicating hypothesis: AS is deemed rare in Black women, so doctors give it little weight as a possible diagnosis. It's hard to include in research what hasn't been diagnosed. The very fact of having to drag from doctor to doctor only makes the next one more suspicious. Minionette Wilson, of Graham, N.C., remembers one rheumatologist who said so explicitly. "He told me that he wasn't going to look at

anything any further than any of the other doctors, that there's no way that anything else could be wrong with me. And he got up and walked out of the room," she recalled. "I just felt so crushed."

Even in online patient groups, where you might share frustration, warn others away from certain clinicians — where researchers often go looking for participants — these women found their experiences questioned. When she'd started out as a health activist, around 2011, Gibson had wanted to get involved in the AS community. She soon backed off, to the more welcoming terrain of chronic pain and invisible disability. "It didn't feel safe for me," she said. "The hostility from a lot of the other patients — this eagerness to have a white illness — was just so strong."

It's gotten better, and she's gone back. Still, she was surprised in 2017 when a special education teacher in Columbus messaged her: She was starting an online group for Black women with AS — a one-stop shop, Taylor-Gentry liked to say, for researchers in search of volunteers. Maybe as a bloc, they could sway the narrative about their disease.



Dawn Gibson, a health writer and patient advocate living with AS, in her home in Royal Oak, Mich.
SYLVIA JARRUS FOR STAT

Excluded

Initially, it was a story written in bone. Anatomists found [skeletons](#) in the church yard or the charnel house showing calcified bridges between vertebrae. A 19th-century neurologist wrote of a back "made rigid as a stick"; a 1930s clinician coined the term

“bamboo spine.” Some have seen hints of it in natural history museums and Renaissance church crypts, in Egyptian mummies and [members](#) of the Medici family. One perhaps overzealous physician posthumously [diagnosed](#) a Cuban crocodile, a Canary Island monk seal, and a prehistoric German cave bear.

With more fine-grained tools for charting DNA, there emerged a fuzzy picture of what might be going on. The disease was found to be associated with a variant known as HLA-B27, in a gene that helps your immune system distinguish other from self. It provides the instructions for a molecule with a notch or groove — a kind of microscopic snag for the protein bits from bacteria and viruses. Once a foreign fragment is caught, it’s dragged to the surface of the cell, signaling for immune backup, sometimes marking the cell for culling, like a pink X spray-painted on a diseased tree.

AS seems to arise from a mistake in what gets snagged, the body reading some of its own protein bits as pathogens — specifically, those shed by the elastic cartilage where bone and stretchy tissue meet. It could be a case of molecular mimicry, attackers evolving ornaments that make them look like shards of ourselves. More often, experts hypothesize a misfolded protein, making the cell’s surface look abnormal and attracting the ire of the immune system. Either way, the result is inflammation that erodes cartilage, and sometimes bone.

The missteps don’t necessarily stop there, though. As Walter Maksymowych, a University of Alberta rheumatologist explained, things can go awry with the construction crew responsible for the gradual regrowth of bone. “It’s over-exuberant,” he said. That was a hallmark of severe AS: Bony spurs and bridges, ghostly white on an X-ray where there should have been the gray of softer tissue. Only over the last two decades, with the subtlety of MRI, did rheumatologists realize how many spondyloarthritis patients they’d been missing. The scans measured water in the body, revealing painful inflammation in joints where there hadn’t yet been visible changes in the bone.

“When we were only looking at X-rays, there was a time when we thought the male-to-female ratio was 9 to 1. We now know it’s 1 to 1,” said Maureen Dubreuil, a Boston University rheumatologist. Why the presentations differ isn’t clear: some murky entanglement of hormones present and genes expressed and environmental factors. What is clear is that these patterns overlap with social ones — namely, women’s experiences being disbelieved. Back pain’s a common complaint, with many possible triggers. MRIs are costly and often inaccessible. Orthopedists or chiropractors might not have auto-inflammatory diseases in mind, or might not associate them with patients who look a certain way. “It leads to women having undiagnosed back pain for decades, if not their entire lives,” Dubreuil said.

Part of a doctor’s job is to make disease visible, to see an explanatory narrative in the impressionistic one a patient gives. Genes have come to play a role in that, too. Variants in over a hundred of them are associated with spondyloarthritis, but HLA-B27 is the most highly correlated, the most well-studied, the one doctors test for. It provides a clue, not a surefire diagnosis. Most patients do have the variant, but you can be HLA-B27 positive and not have the disease, just as you can have the disease and be negative for HLA-B27. In some physicians’ minds, though, the variant and the disease have become synonymous, erasing the subtleties: You don’t “have the gene,” so it’s got to be something else. A smaller proportion of affected Black patients are thought to be positive — another potential hurdle in getting diagnosed.

Those genetics studies also revealed something else. The link with HLA-B27 first emerged in April 1973, in two papers published just weeks apart. The illness was already described as unusual in Black patients — and rarity became an excuse for exclusion. [One study](#), from London, was looking at “undoubted, classical” AS: Along with anyone who had gut or skin issues, the researchers wrote, “Non-Caucasians were excluded.” The [other](#) came from Los Angeles. It mentioned testing Black patients, but their results were reported “in addition to this Caucasian series” and not part of the statistical analysis — an afterthought. Even into the ’90s, some [research elucidating](#) this sort of association was explicitly limited to white participants. The assumption of separateness was embedded in the design.



A scan of the lumbosacral junction in a patient with ankylosing spondylitis.
WELLCOME

‘I wanted to be the majority’

Taylor-Gentry had grown up caught between worlds. There was the world of Lanier, where she wished she weren't Black, where she wished she could be like everyone else, the girls arriving with their hair down and still wet. Then there was the world of her grandmother's house, a hub for the local chapter of the country's oldest Black sorority, where impossibly regal ladies gathered to plan voter registration drives, where she learned to make Parker House rolls, indenting them with a butter knife, gently folding the dough to achieve the right airiness.

Her grandfather had survived the Tulsa Race Massacre. He never talked about it. She only found out when she learned about it in school, and asked her grandmother, who said that her granddad had just escaped it. It was 1921, and he was 10. Aided by the authorities, a white mob tore through Greenwood, murdering hundreds, leaving thousands homeless. Before, it was a prosperous neighborhood, “the Black Wall Street.” After, little was left but rubble and smoke. Taylor-Gentry's grandfather had been scooped up by a couple as they were fleeing, and brought to the convention center, which had turned into a kind of displaced persons' camp.

By the time Taylor-Gentry arrived in school, the city's desegregation plan was less than a decade old. “They weren't dragging their heels, they were dragging their whole feet,” said community advocate Julius Pegues, of school officials. When a federal judge ordered them to make a plan, their response was to close Carver, a Black middle school. To Pegues, that was an affront, an attempt at erasure: “We knew, and we still know, that when you close schools, communities die.” He and other parents spent three weeks cleaning a donated church building to create Carver Freedom School. They raised money to hire a certified principal; they paid teachers the same wages as Tulsa Public Schools. By the next semester, the Tulsa school board had a new plan that involved reopening Carver.

Her cousins in Kansas City mocked her side of the family for not being Black enough. One, Melissa Vaughns-Guein, remembers Taylor-Gentry's father moving to a suburb that was “the whitest of the white” — “I can't jog in the neighborhood where my uncle lives,” she said. That sort of comment didn't faze him. He worked for IBM. He's always been unflappable.



Smoke billows over Tulsa, Okla. in this 1921 photograph taken during the Tulsa Race Massacre. Hundreds of people in a prosperous Black business district were killed.
ALVIN C. KRUPNICK CO./LIBRARY OF CONGRESS VIA AP

But he didn't want Taylor-Gentry to go to a historically Black college or university. Her sister had picked out Langston, where their maternal great-grandfather had taught tailoring, where her maternal grandmother had studied, and he knew better than to object to that. In the other twin, he saw his chance. He told her she'd be better off at a PWI — a primarily white institution — and chose one for her, needled her until she was convinced. “Because in that era, for my parents, white was better,” she said. “My dad did not feel that people were going to look at my degree as a substantial degree because it was a from a Black university.”

She did poorly. She felt like she was adrift. When an ad for an HBCU in Ohio popped up on TV, it caught her eye. She had an aunt in Columbus, and with her help, she arranged for a clandestine transfer to Central State. “I didn't tell my father. I told him I was going to go spend the summer with my Aunt Angie and work,” she said. She moved all her stuff there. She fully enrolled. Then she let her father know. “My dad was like, ‘Naw, just come on back.’”

She stayed. She'd been scared, beforehand. Her cousins had made fun of her for talking so white. She worried that even there, she'd be out of place. Once she met her roommate, though, the anxiety slipped away. It felt right. “I didn't want to be the minority anymore,” she said. “I wanted to be the majority.”

A ‘paucity of data’

One Tuesday in May 2017, Taylor-Gentry posted a message in one of the larger ankylosing spondylitis support groups on Facebook. She’d roamed from group to group herself, looking for one that would feel comfortable, from online AS forums to those for rheumatological diseases more generally, even one for a disease she didn’t have but with similar symptoms. Now that she was starting a new one, she figured that there might be others like her on the sidelines of all these places, who’d been told their case was unique.

“My name is Christi and I have a support group for Black women who have AS,” she wrote. The purpose, she went on, was “to have a place to gather and hopefully gain the medical community’s attention to have our specific needs met.”

Many were supportive. The group’s administrators applauded the idea. But the first comment to pop up was an illustration of why she wanted to start a new group in the first place. It accused Taylor-Gentry of being “really a little racist.” Another patient reacted to her message with a thumbs-down. “So much for supporting each other ... dividing each of us is definitely not a good idea ...” the person wrote. Another patient commented, “I thought we are all kindred people, trying to support each other ... no matter what color we are. Very disappointed” — and added a sad-face emoji. The first commenter returned to say that if she’d founded a white-only group, there would be an uproar.

It’s a common kind of [backlash](#): White people [accusing](#) those who identify systemic racism as themselves being racist and sowing division. It’s often used to paper over real injustices at play. Labeling equity efforts as attacks is a way — unconsciously or not — of maintaining the status quo.

At its heart was an ignorance of the long tendrils of history, how those loops and coils wind through the everyday. Again and again in her responses, Taylor-Gentry explained that her motivation was not one of superiority or exclusion. Her group was not anti-anyone. Rather, it was trying to make visible those whose experiences had gone unseen or been erased.

She and others also wondered whether the disease might manifest differently in some Black patients than it did in many of their white counterparts — a question the group might help answer. It had been raised in the scientific literature, too. One 2017 [study](#) found that in just about every analysis — measures of inflammation, tests showing how well you could move through daily activities — the Black patients had, on average, more severe illness. A similar finding was [published](#) by a different team in 2020.

**“The longer we wait to diagnose people,
the harder it is to treat them.”**

LIANNE GENSLER, RHEUMATOLOGIST AT UCSF

While the authors of the second study thought there was some sort of largely genetic effect being picked up, other rheumatologists wrote a [letter](#) to the journal, suggesting a different hypothesis: “It is possible that a higher proportion of African American patients with less severe disease failed to be diagnosed with AS compared to whites.”

It could also be that the years spent searching for a diagnosis allowed inflammation to wreak havoc unchecked. As Lianne Gensler, a University of California, San Francisco rheumatologist, and an author of the 2017 paper, explained, “The longer we wait to diagnose people, the harder it is to treat them.”

More recent research has hinted that access to care is one possible explanation for the gap in disease severity. “We know the prevalence is lower in patients who are Black, but also in patients who are Medicaid enrollees,” said Ogdie, the University of Pennsylvania rheumatologist, who published a [paper](#) analyzing race and insurance coverage in spondyloarthritis earlier this year.

Her study couldn’t specifically pick up underdiagnosis — it’s hard to search a database for an absence — but the numbers seemed to suggest it might be lurking there. If being poor enough to qualify for Medicaid meant you were less likely to have a disease, chances are that had less to do with whether the signs were in your body, and more to do with how hard the medical world made it for you to enter and navigate. In [2019](#), 15% of white non-elderly Americans were on Medicaid, while 33% of Black Americans were.

The question involves all sorts of variables that need untangling. Researchers running spondyloarthritis clinical trials say it’s even harder to recruit Black volunteers than in other areas because they make up such a small sliver of the patient population. With greater numbers comes more reliable findings. As Paras Karmacharya, a Vanderbilt University rheumatologist, wrote in an email, “we still do have a relative paucity of data for racial/ethnic groups in spondyloarthritis in general.”

‘A huge incentive’

Taylor-Gentry’s group now has around 240 members, and 30 new ones waiting to be vetted and let in — not huge, but well beyond the 20 Black women with AS her

rheumatologist had told her there were in the U.S. So far, no scientists have reached out. But patient activists for other diseases have shown that the idea can work as a way of bridging the gaps between underrepresented patients and researchers.



Taylor-Gentry stands in the classroom where she teaches special education in Dallas.
JERSEAN GOLATT FOR STAT

For Teresa Akintonwa, it worked perhaps too well. She'd founded Black Covid-19 Survivors on Facebook, a place where they could discuss the long Covid symptoms that their doctors and employers weren't taking seriously. It grew to 1,600 members — and Akintonwa's inbox filled with requests from doctors and neuroscientists and anthropologists. At first, she allowed a number of them to join the group, to recruit for their research. She wanted to empower members, to help inform the scientific community about what they were going through and spur research that might result in treatments. "But it began to feel like people were just kind of coming to take, take, take," she said.

She wishes that more of them had been explicit about their goals from the get-go, and had returned to the group to share results. "In a way, I became offended," she went on, "because we were right back to where we were at the beginning, where the health care

— or your research — is not really about us. This is about you trying to check off things on your agenda to say that you did it.”

Some in the ankylosing spondylitis group feel a similar sort of disenchantment. But that doesn't mean they don't see research as a way to get medicine to take their pain more seriously.

Tolliver, whose diagnosis took 30 years, sits on paid patient advisory boards for two pharmaceutical companies, but she has no illusions about the economics at play. To her, if the biomedical world is creeping toward the inclusion of Black women with ankylosing spondylitis, it's at least partially because they represent an untapped market. “We wouldn't even be having this conversation if the pharmaceutical companies hadn't come up with these biologics 20 years ago,” she said. She sees them advertised everywhere: On swag in doctors' offices, during commercial breaks, online. Her family and friends keep calling to say, “I saw your medicine on TV!” A number of those immune-suppressing drugs have a list price over \$71,000 a year.

“There's so much money in this treatment. So there's a huge incentive,” she said. As she sees it, her presence in those company focus group meetings is linked to that. “Not because they love Black people, or women, or really want to help us. They're in business to make money. It's called Big Pharma for a reason. And I'm not mad at it. Because, you know, I wouldn't be able to live my life the way I live it without it.”

Wilson, who'd had a rheumatologist walk out on her after seeing her file, works as an administrative assistant at Duke's medical school, and makes a point of speaking to the students. To her, that's where the problem starts. “There are a lot of copays wasted because a doctor won't look beyond what they were taught,” she said, adding, “I just don't believe that a patient should be dismissed as drug seeking or invalid, just because they don't have the right race or sex.”

Dedicated space

Taylor-Gentry tried going back to Tulsa. She tried teaching in the public schools where she'd grown up, but it didn't feel right. She loved showing kids how to draw a lattice-like grid in which to calculate double-digit multiplication, breaking down the problem into smaller, more visual steps. She loved nudging them toward a steadier rhythm in their reading. But arriving in Tulsa, she felt like her approach and the school's didn't gel.

She lives and works in Dallas now. She sometimes wishes she spent her whole week in a dedicated space, as she had in Columbus, a resource room for the kids with

individualized education programs, rather than crouching by desks in the general classroom, helping them untangle the work they've been assigned. About once or twice a week, though, she'll pull a few students out and break concepts down, step by step, how to understand what volume is, how to calculate the volume of a cylinder or a cone.

The ankylosing spondylitis group happens in her off-hours, whenever she has time. Sometimes, it's quiet. There are moments when it feels as if they've examined so many instances of medical racism — turned each one around and inside out, compared notes, strung them together to depict the general sweep — that they've exhausted the topic. But then a new person joins, or someone has a bad flare-up, or a peculiar symptom, or an offensive interaction with a doctor, and makes a post. There's a flurry of comments and emojis and likes, a kind of online answer to a medical chart full of physician skepticism: “patient complains of,” “patient claims that,” professionalized phrases that make a bodily sensation sound like it isn't real. There are no dismissals of pain, no accusations of hypochondria.

Not all posts are about ankylosing spondylitis. When someone was navigating a tricky relationship with her stepson, there was a swirl of parenting advice. When Taylor-Gentry wrote about her twin sister's passing from Covid-19, there was an outpouring of shared grief.

Even when there isn't much activity, when everyone's busy, its mere existence is a comfort, as if it were a familiar place you can return to and feel at ease in, somewhere that is unquestionably yours.