

This woman's wracking cough baffled a small army of specialists

By **Sandra G. Boodman**

March 21, 2020 at 10:00 a.m. EDT



By the time Lisle Hannah consulted lung doctor Christopher Wyckoff in November 2017, she had seen a small army of Washington-area specialists: two allergists, a gastroenterologist, a pair of internists and three other pulmonologists.

Doctors had probed her upper GI tract, peered into her lungs and challenged her airways to check for asthma. Hannah had submitted to numerous blood tests, taken multiple medications and undergone scans and X-rays of her chest and sinuses.

Yet despite an extensive work-up, the cause of her severe cough had not been identified. For more than two years, the federal employee, now 54, had battled a wracking cough that drew uneasy stares or expressions of sympathy from those who heard it.

“My friends kept asking, ‘What is this thing?’ ” she recalled. “It was ever-present.” “My friends kept asking ‘What is this thing?’ ” said Lisle Hannah of her baffling cough. “It was ever-present.”

The Northern Virginia resident said that for a long time she was more exasperated than alarmed. “I wasn't worried,” Hannah said. She assumed that eventually one of her doctors would figure it out. Wyckoff had a distinctly different reaction. Although accustomed to seeing patients with a chronic cough, one of the [most common conditions](#) in medicine, he was struck by the sheer number and variety of specialists who had been stumped by Hannah's case.

“When I met her for the first time, I looked at her and thought, ‘Oh my gosh, what is going on?’ ” It would take Wyckoff four months to answer that question.

“It was,” he recalled, “quite the adventure.”

Might be reflux

Hannah's cough started suddenly in September 2015, just before a business trip.

“It sounded horrific,” she recalled. She had taken medication for asthma since she was 4 and over the years had experienced occasional bouts of pneumonia and bronchitis.

“To me, this sounded bronchial,” she said. A chest X-ray at an urgent care center found no sign of infection. A month later, a physician assistant in her primary care practice ordered a short course of steroids. When that didn’t help, he referred her to an allergist, who prescribed an antibiotic.

Hannah continued to cough. Two months later, the allergist prescribed another round of steroids and changed her asthma medications.

He also ordered a series of blood tests, including one for [aspergillus](#), a fungus that can cause a respiratory infection. The blood tests showed nothing. Neither did a high resolution CT scan of her chest.

“I started asking doctors whether I was contagious,” Hannah remembered. She felt reassured when they told her there was no sign of an infection, such as tuberculosis, which she could transmit to others.

“In meetings I would be sitting there talking and this humongous cough” would erupt, she said. Sometimes it woke her in the middle of the night.

For the next 10 months, allergists in the two-doctor practice prescribed several combinations of drugs to treat asthma. One added an acid-blocking medicine on the theory that the cough might be the result of gastrointestinal reflux.

A new internist suggested that the drugs Hannah took to control her high blood pressure might be causing the cough. She switched her medications, which had no effect.

In May, Hannah’s gastroenterologist performed an upper endoscopy, a procedure that uses a fiber-optic camera to inspect the digestive tract for abnormalities. When he found nothing, he suggested doubling the dose of the proton-pump inhibitor she had been taking for reflux. Four months later, Hannah was still coughing.

One allergist then suggested she might have developed a new allergy, but testing revealed nothing. Hannah was still allergic to the same things — dogs, cats, mold and pollen — that had been found when she was a child.

In February 2017, she saw the first pulmonologist. He ordered the gold standard test for asthma — a [methacholine challenge](#) — which measures lung function and airway constriction. The test found no evidence of asthma.

An 'existential crisis'

Hannah was incredulous — and skeptical. “For 49 years I had had asthma,” she noted, joking that the result triggered an “existential crisis.”

One possibility is that Hannah had [outgrown asthma](#) — if she had it at all. The pulmonologist proposed that her cough might be the result of [eosinophilic bronchitis](#), which resembles asthma. The other possibility, which he considered more likely, was an overly sensitive larynx.

The pulmonologist prescribed gabapentin, a medication originally approved to treat seizures now [widely prescribed for unapproved uses](#), including chronic cough. Hannah took it for two months; other than making her feel “very foggy” it had no effect.

Next stop was an ENT. A scan found a [deviated septum](#), which is linked to recurrent sinus infections, but not the kind of cough Hannah was experiencing. The physician assistant who inspected Hannah's larynx heard wheezing and recommended that she return to a lung specialist for a [bronchoscopy](#), a procedure that uses a fiber-optic camera that allows doctors to inspect the lungs and take tissue and fluid samples.

Hannah saw a second pulmonologist in a different practice; he ordered the bronchoscopy, which was performed by one of his partners.

Cultures showed that Hannah's lungs were infected with two common bacteria: *Haemophilus influenzae* and *Staphylococcus aureus*. The second pulmonologist, who was on the verge of retirement, prescribed three weeks of one antibiotic and when that didn't work, seven weeks of a second drug.

By the time she saw Wyckoff, the fourth lung specialist in less than a year, Hannah's cough was so severe she was retching.

Which bacteria?

Wyckoff sent Hannah for a second CT scan of her chest and blood tests to screen for possible rheumatological or immunological diseases. There was no sign of either, but a CT scan found mild [bronchiectasis](#), a chronic disease that causes lung scarring and repeated infections because of an inability to clear mucus.

Wyckoff recommended a second bronchoscopy, which he performed in late November. This time cultures found staph aureus and a rare bacterium called [Stenotrophomonas maltophilia](#), typically found in people with compromised immune systems.

By January 2018 Hannah was feeling worse. "My days were really changing," she recalled. "I felt miserable. This was becoming a way of life."

Wyckoff recommended another bronchoscopy — her third in six months — and referred Hannah to an infectious disease specialist, whom she began seeing in tandem with Wyckoff.

"It's very unusual to do [multiple] bronchoscopies, but we kept getting different bacteria," Wyckoff recalled.

He was puzzled: Hannah didn't have asthma, there was no indication of rheumatological disease or immune dysfunction, yet she was still coughing and had developed pneumonia that was resistant to multiple antibiotics.

"At that point, I didn't know what we were dealing with," he remembered. "I told her I wasn't going to give up on her and that we are going to solve this." Hannah, he added, "was patient with me" and displayed a sense of humor, "always trying to make light of the situation."

The results of the third bronchoscopy pointed to a new possibility, one that would explain the persistence of her cough and the reason previous treatments failed. Cultures revealed the presence of a [mycobacterial infection](#).

But which one? It would take weeks to grow a culture necessary to pinpoint the type of infection, which was necessary to guide drug treatment.

Mycobacteria that cause lung disease are ubiquitous in soil, water and dust and typically do not cause illness. But some people are susceptible to infection because of preexisting lung problems, including bronchiectasis, cystic fibrosis or chronic obstructive pulmonary disease. The use of immunosuppressive drugs, including steroids, has also been linked to mycobacterial infections.

A new possibility

In Hannah's case, a culture grew *Mycobacterium abscessus*, which health experts classify as an emerging disease. First identified in 1992, the bacteria can affect the lungs or skin. It can be hard to treat because it is resistant to most antibiotics and may require months of rigorous drug therapy that many patients are unable to tolerate.

As in Hannah's case, the source of infection is frequently unknown.

Hannah was told she would need a year of antibiotics. One drug would be taken orally while a second, *Amikacin*, would be administered through a catheter called a *PICC line* which was surgically implanted in her upper arm. Hannah would be trained to give herself daily hour-long infusions. Because Amikacin can cause permanent hearing loss, she would need to undergo a hearing test every two weeks.

By mid-March, she was feeling much better. A month later, a test showed slight hearing loss. But by May her hearing loss had worsened significantly. Doctors discontinued the Amikacin and switched drugs. A week later, Hannah developed another serious problem: her skin was weeping, indicating breakdown around the site of the PICC line. The line was removed and Hannah began taking oral antibiotics.

But within a week on those, she developed a severe rash that doctors suspected was a drug allergy. Because she had greatly improved and testing showed no signs of an infection after three months on antibiotics, doctors told her to stop taking the drugs. Continuing was deemed too risky. In June, Hannah said, the cough that had dogged her for nearly three years finally stopped altogether. It has not returned, although recurrence remains a possibility, Wyckoff said.

"The further out she goes without symptoms, the better," he added. "That's why we like people to finish therapy. But many cannot tolerate the side effects."

Hannah said she feels well and is optimistic her infection won't recur.

If it does, she said, she may take the advice of her infectious disease doctor and head to National Jewish Health in Denver. The internationally prominent research hospital specializes in treating respiratory diseases.

Hannah said she remains grateful to Wyckoff whom she found to be steadfast and reassuring. The experience, she quipped, taught her something else: "Look for a doctor whose last name works with your symptoms."