

(Cameron Cottrill for **The Washington Post**)

[Health & Science](#)

# Doctors thought it was a simple foot infection. They were so wrong.

By [Sandra G. Boodman](#) August 22 at 12:41 PM

Melissa Curley Bogner was baffled: Why did her feet feel suddenly hot — in January?

The 41-year-old management analyst for the Navy had grown accustomed to periodic bouts of neuropathy — numbness in her hands and feet — the apparent legacy of a severe allergic reaction to a drug she took in 2000 to treat a gynecological infection.

But this 2015 episode was different. Along with the sensation that her feet felt unusually warm, the skin on the second toe of her right foot looked inflamed. Weeks later, she noticed a small blister.

Bogner, who lives in Southern Maryland, initially shrugged it off. She figured that whatever was wrong would go away on its own.

“I didn’t go to the doctor because it didn’t hurt,” she recalled. But eight months later, Bogner would learn that her foot problems were classic signs of a condition that was neither temporary nor trivial.

“It’s been life-altering,” Bogner said of the diagnosis. Summer, a time of year Bogner once eagerly anticipated, has become the season she finds hardest to endure. To cope with her new reality, she has sought to channel her energy into a self-help group for people diagnosed with the little-known malady.

A fungal infection?

At first, Bogner tried to largely ignore the problem, assuming that her shoes were to blame. Changing footwear didn’t help. Sometimes her toe would itch and feel tingly. At other times, the redness seemed to lessen, but it never disappeared entirely.

In April, when she took her son to an urgent care center for treatment of a skateboarding injury, she asked the doctor what he thought might be wrong with her toe. He told her it looked like a [fungal infection](#) and suggested she try an over-the-counter remedy. Bogner took his advice but discovered that the ointment irritated her toe. Instead of clearing up, there were signs that the redness was spreading to her third toe.

At the time, Bogner was preoccupied with more pressing medical problems. During a three-day hospitalization for a hysterectomy, she asked doctors about her toe. They were reassuring; if it was serious, Bogner said they told her, the problem would affect all her toes, not just one or two.

By the end of May, her toes were still inflamed and her feet felt so hot that she routinely removed her shoes while she was sitting down.

Bogner consulted her primary-care doctor. He, too, suspected a fungal

infection and prescribed a potent cream containing a [corticosteroid](#) in the hope that it would quell inflammation.

In fact, Bogner said, the cream, which she used for about a month, exacerbated the problem. What had been a small blister “blew up into a cyst on the top of my toe,” she said. The sensation of heat and the tingling were undiminished.

“I thought, ‘When is this toe going to give me a break?’ ” Bogner recalls.

Next stop was a podiatrist, whom Bogner saw in June. By then, three toes on her right foot sometimes turned crimson and the problem seemed to be affecting her left foot as well. The podiatrist was concerned that although Bogner did not have [diabetes](#), her toe discoloration might signal a vascular problem that was impeding circulation in her legs. She sent Bogner to a cardiologist.

Testing by the cardiologist found nothing to account for the skin discoloration or tingling, such as [peripheral artery disease](#). “I thought, ‘I’m back to square one,’ ” Bogner recalled. By this time, the problem had spread from her toes to the rest of her feet.

Increasingly alarmed, Bogner said she “began obsessively Googling ‘burning red feet.’ ” One possibility was a condition called [small fiber neuropathy](#), a form of peripheral neuropathy that can cause a burning sensation and severe foot pain.

Another option was [erythromelalgia \(EM\)](#), a rare and poorly understood disorder; the term literally means “red limb pain.” First described in 1878, the condition is characterized by red, hot and painful extremities, usually the feet and less commonly the hands. In some patients, the ears or face are affected.

Some EM cases are caused by a genetic mutation, while others are the result of a blood disorder, including [thrombocytosis](#), which occurs when the body produces too many platelets, disrupting normal clotting. But many people develop EM for no discernible reason. There is no cure for the disorder, which causes abnormalities in the way blood vessels dilate and constrict. Symptoms range from constant and extremely painful to intermittently bothersome; treatment largely consists of drugs to blunt the pain from flares and to help patients sleep, and of functional measures such as avoiding heat and elevating the legs.

Numbers are imprecise, but EM is estimated to affect about 1 in 100,000 Americans, many of them white women who develop the condition in middle age, although some people are affected as children. “I thought, ‘I can’t believe that I’m that 1 in 100,000,’ ” Bogner recalled, fearing that in fact she was.

Desperate for guidance, Bogner called the [National Organization for Rare Disorders](#), a Connecticut-based clearinghouse and advocacy group that provides information about more than 1,200 conditions, including several of the possibilities Bogner had found. A staff member suggested she print out the information about EM, which most closely matched her symptoms, and take it to the neurologist she had seen over the years for treatment of her neuropathy. She was also advised to take pictures of her red feet during a flare to show the neurologist.

Ahmed Kafaji, a neurologist who practices in St. Mary’s County, saw Bogner in early July.

Her hands, he recalled, looked fairly normal but felt hot. When she showed him cellphone pictures of her feet, their appearance was

consistent with EM, which he had seen previously once or twice in his career. Kafaji said he also noted that the skin on Bogner's hands seemed somewhat coarse, which is consistent with EM.

“If doctors haven't seen a case, it's often misdiagnosed as eczema or allergies,” he said. As a result, some patients go from doctor to doctor without an accurate diagnosis.

Kafaji said he was concerned that Bogner might have an underlying blood or autoimmune disorder. So the following month, Bogner drove to Johns Hopkins Hospital in Baltimore, where she sought a second opinion and testing to rule out other abnormalities.

Blood tests ruled out cancer, Lyme disease, various autoimmune or bone-marrow problems, and a genetic mutation known to cause [EM](#). After seeing two neurologists, a rheumatologist and a hematologist, Bogner was told that she had primary idiopathic EM — meaning the cause was unknown.

‘A dreadful season’

The definitive diagnosis plunged Bogner into the despair that can accompany the wrenching adjustment required to live with a disabling, possibly permanent, condition.

While EM can improve, or even largely disappear, that doesn't happen often.

A [study of 168 patients](#) treated at the Mayo Clinic between 1970 and 1994 found that 10 percent reported that their EM resolved after an average of nearly nine years. Of the others, about one-third reported that it worsened and one-third that the problem improved but did not disappear. The rest reported no change.

Bogner's condition has not improved. She takes medicines to help her sleep and to try to blunt the worst of the flares, which can last from five minutes to all day.

"The heat can be like submerging your toes into burning water," she said. When her ears are affected, "it feels like my head is on fire."

Avoidance is a key strategy; she stays out of the summer heat and sun, which can trigger a flare, and remains in air-conditioned settings as much as possible. Last week, she and her family ventured north for their first vacation in Maine.

"Summer is a dreadful season," she said. Trips to the pool or beach are now out of the question. Alcohol and spicy food can trigger a flare, so Bogner largely avoids both, but misses having a glass of wine with friends.

She holds out hope that there will be more effective treatment in her lifetime. "Doctors don't understand the depression that goes along with this," she said.

Involvement in an online group has been her most important source of support, Bogner said, and has enabled her to feel less isolated and lonely and to help others in similar or more difficult circumstances.

"We talk people off the ledge," she said. "Our bond is very strong."

*Submit your solved medical mystery to [sandra.boodman@washpost.com](mailto:sandra.boodman@washpost.com). No unsolved cases, please. Read previous mysteries at [wapo.st/medicalmysteries](http://wapo.st/medicalmysteries).*