The searing pain took 10 days to move from the man’s toes across his entire body, creating a sensation that felt “like sunburn rubbed with steel wool.”

Another man, whose legs have come to feel thick, heavy and hard to move “like tree trunks,” tied the much slower progression of the condition in his body to toxins he inhaled while working as a fire marshal at the World Trade Center on September 11, 2001.

And it’s been 15 years since a woman with the same affliction noticed that she would walk out of her shoes because she couldn’t feel her feet.

“I’m trying to stay positive even though my neurologist told me to go home and pray,” said Carolyn Burgess, 61, of Spartanburg, S.C.

All three have peripheral neuropathy, a term that encompasses a range of disorders that injure the nerves that affect the use of one’s limbs. In the United States, the disease affects nearly 20 million people, which is more than are affected by multiple sclerosis worldwide.

Peripheral neuropathy was discovered more than 100 years ago, but until recently it has remained relatively unknown beyond its victims and the doctors who treat them.

“It’s been the stealth disorder,” said Donald G. Jacob, executive director of The Neuropathy Association in New York.

Johnny Cash, Julia Child, Janet Leigh and Bobby Short all had the disease. Mary Tyler Moore has it, too. Andy Griffith had an acute form, Guillain-Barré syndrome, which can lead to paralysis and respiratory failure.

But no celebrity has stepped forward to put a national spotlight on the disease the way Michael J. Fox has for Parkinson’s disease and Montel Williams has for multiple sclerosis. Some engaged in the fight against peripheral neuropathy believe that has compounded the difficulty in improving diagnosis and treatment.

Doctors first told Cash he had Parkinson’s disease. Later, they said he had another rare condition, Shy-Drager syndrome.

“Now they say it’s autonomic neuropathy,” Cash said when he finally discussed the disease in an interview with Universal Music while promoting his final album in 2003. “I’m not sure what that means, except I think it means that you’re getting old and shaky.”

Without a proactive celebrity face, change is slow, but it is coming.

The Neuropathy Association lobbied Congress successfully last year to increase funding to the National Institutes of Health (NIH) for research of neurological diseases by $51 million. Next year, the NIH is expected to spend $1.5 billion studying such disorders.

The most common forms of the disease are triggered by diabetes, autoimmune reactions, cancers, AIDS, toxins, viruses and nutritional imbalances. “Although diabetes is the most common cause, 20 percent are ‘idiopathic,’ meaning no specific origin can be found,” said Dr. Thomas Brannagan, Cornell University.

Though there are many causes and types of neuropathy, patients usually experience similar symptoms. Sufferers of one common type develop a lack of position sense.

“I cannot close my eyes and maintain my balance,” said Irene Beer, 70, of New York. “I need grab bars and a seat in the shower.”
Treatments vary, but they generally start with drugs like the anti-seizure medication Neurontin for pain management. Then, doctors often prescribe corticosteroids like prednisone and treatments like blood plasma exchange and intravenous infusion of immune globulin to stall progressive nerve injury.

One challenge for healthcare providers has been to inform the public of symptoms and possible treatments. Groups such as The Neuropathy Association and braintalk.org use the Internet to offer patients educational and emotional support, but there are many instances in which the disease has been misdiagnosed as multiple sclerosis, lupus or Lou Gehrig’s disease.

“With sensory symptoms, especially those of neural pain, most physicians not familiar with neuropathy—and that’s most of them—tend to think of multiple sclerosis first, or maybe spinal compression, and if tests for those don’t pan out, they have little idea what might be going on,” said Glenn Ribotsky, a patient with the disorder.

“It took the skin biopsy three months after the onset to document that I have a small-fiber sensory syndrome.”

Neurologists who specialize in the disease are frustrated that health insurance plans increasingly rely on evidence from blinded controlled medical trials before they will cover treatment. With peripheral neuropathy, there aren’t enough such trials from which to draw evidence. Dr. Norman Latov, of Cornell University, has diagnosed several patients with demyelinating polyneuropathy, but their insurance would not cover treatment. "‘Evidence-based’ guidelines is doublespeak because guidelines use evidence selectively," Latov said. “Clinical treatment develops through experimentation and observation. We need to do what we need to, to help patients.”

Yet, Latov said, it is an exciting time for research. Last year, the FDA approved Cymbalta for pain from diabetic neuropathy. It is the first drug specifically for the disease. “Hopefully, there will be more work in neuro regeneration,” Latov said.

Joe McAuley, 47, the man whose legs felt like tree trunks, found relief for foot pain with a device that electrically stimulates nerves. McAuley also takes vitamin B supplements. He said his feet feel somewhat better, though his condition played a part in his decision to leave the New York City Fire Department in 2003.

Ribotsky, 44, the man with pain that moved from his toes to his entire body, said the pain has dwindled now that he takes megadoses of the drug Neurontin. When it does flare up, he said, his hands, feet, left shoulder and abdominal muscles hurt as though he has had a series of bee stings.

Burgess, whose doctor told her to go home and pray, broke both ankles when she fell due to poor balance. She uses a walker both inside and outside her home. Burgess said she was devastated that she had to give up singing in her Baptist church because she feared falling from the choir loft.

“When you can’t do ordinary things for yourself, it takes the stuffing out of you,” Burgess said. “I have faith God is going to use this for some good, because it would be easy for me to give up hope and not try.”

Because neuropathy is finally moving onto the public’s radar screen, perhaps someday soon there will be an articulate, notable advocate who will give Burgess, and all those who suffer from neuropathy, hope for more research and better treatment. ■