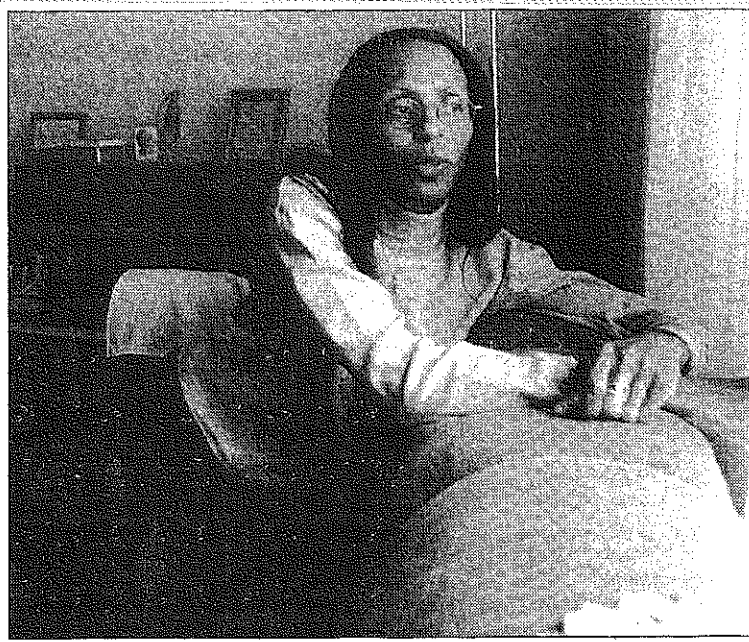


By Spencer Ainsley, Poughkeepsie (N.Y.) Journal, for USA TODAY

Staying the course: Rebecca Moore, 22, has fought chronic fatigue for nine years; tutors and a computer have helped her earn school credits from home.



By Anne Ryan, USA T

Written off: The disease sometimes leaves former nurse Barbara Brock so exhausted she can't clean her house, but 'so many people still don't believe it.'

Real life with a 'phantom disease'

More sufferers don't mean more answers about chronic fatigue

By Kathleen Fackelmann
USA TODAY

Terry Hedrick will never forget May 9, 1994, the day she came down with the sore throat that would change her life.

She had never heard of the baffling illness called chronic fatigue syndrome, and so gave her raspy throat little thought at first.

But the days stretched into weeks and months. Hedrick suffered from debilitating fatigue, painful headaches and confusion. She tried to keep working as the director of a research group at the U.S. General Accounting Office in Washington, D.C. But eventually the illness was too much.

"I went out at age 45 — at the height of my career," the 51-year-old Hedrick says.

Experts in the field say that many people, including doctors, write off people like Hedrick, attributing their symptoms to "phantom disease."

But a study published in the fall suggests the syndrome may be more widespread than previously indicated. While the federal Centers for Disease Control and Prevention (CDC) estimates 500,000 sufferers, a Chicago researcher argues that the number may be more than 800,000.

Chronic fatigue syndrome was tagged "yuppie flu" during the 1980s, when the media picked up on the mysterious disorder. At that time, studies suggested that the illness mostly struck upper- or middle-class white women. The CDC then said the disease appeared rare.

Yet Leonard Jason, a researcher at DePaul University in Chicago, knew from the CDC that about 3,000 Americans per month called to ask about the illness in the early 1990s.

"It looked like an epidemic was going on," he says.

In 1993 he began a study in which his team called more than 28,000 households in the Chicago area. Those who said they had suffered long-lasting fatigue were brought in for a detailed medical exam.

Further screening yielded 32 people in the study who met the definition for chronic fatigue syndrome.

Most had never heard of the illness.

"They know they're sick, but they don't know what's wrong," Jason says. "To me, that's an alarming situation."

His study suggests a rate of chronic fatigue syndrome of 422 per 100,000 people in the USA.

Jason's study also found the disease cuts across racial lines. Mexican Americans and Puerto Ricans had the highest rates, followed by black people, his team found.

Barbara Brock, 52, of Evanston, Ill. — who is neither white nor a yuppie, but a black former nurse — has the syndrome.

Sometime after a 1992 injury at work, Brock started suffering from fevers, sore throat, enlarged lymph nodes and a bone-wearying fatigue. She drank so much coffee to meet her work obligations that it made her sick. Eventually she quit her job. Now there are days when she can't get out of bed.

Brock feels written off by the medical profession. Time after time, she has left a doctor's office in tears.

"So many people don't believe it," she says. "They still have the attitude that women are hysterical."

In Jason's study, as in others, women were much more likely to get the disorder than men. No one knows why the gender difference exists. But men do get the disorder.

The study also shows that certain age groups get the disease more often, with baby boomers facing the highest risk.

Younger people, though, are also susceptible.

Rebecca Moore of Hyde Park, N.Y., 22, got sick in 1991, when she was 15 years old. By December of 1992, the high-schooler couldn't get out of bed. It took another year for Moore to get a diagnosis.

Moore says most kids with this disease get labeled as fakers. Yet the teachers at Moore's school never doubted their former A student. They helped her get home tutors so she could finish high school.

"It took me five years," she says about her high school diploma. No small achievement, considering that for the first five years of her illness Moore got no treatment for the pain and forgetfulness it brings.

"I couldn't remember a whole sentence," she says.

Since that time, Moore has been able to pursue a college degree with the help of a home computer.

"There is no cure," she says. "But life can be made more manageable."

Moore's perception that many people view chronic fatigue syndrome sufferers as "fakers" is common, and part of the problem when it comes to giving serious study to the ailment, experts say.

"Many physicians look upon them as malingerers, complainers and whiners," says William Reeves, director of the CDC program on chronic fatigue syndrome in Atlanta. "It is a real and disabling illness," he says.

But it's one that remains riddled with uncertainty, including the lack of a diagnostic test, says Anthony Komaroff, a chronic fatigue syndrome expert at Harvard Medical School in Boston. Instead, a diagnosis rests on a definition of the illness.

Doctors agree that people with chronic fatigue syndrome must suffer from severe, unexplained, fatigue that lasts at least six months.

Symptoms include sore throat, muscle and joint pain, headache, short-term memory loss and sleeping difficulty.

Doctors can partly relieve the symptoms of chronic fatigue syndrome, says Nancy Klimas, an immunologist at the University of Miami School of Medicine. Many sufferers have a blood-pressure abnormality that results in light-headedness, nausea, and fainting, for example. The simple addition of salt to the diet and medication may help, Klimas says.

Such tricks are not a cure, of course. For that, researchers must determine what causes the illness.

One leading theory is that an infectious agent, a virus for example, kicks off the disease. The invader damages the immune system and leads to an overactive immune response — one that produces all of the symptoms of the flu, even after the virus is long gone.

Kimberly Kenney, executive director of the Chronic Fatigue and Immune Dysfunction Syndrome Association in Charlotte, N.C. calls it the "hit and run" theory. While many viruses have been implicated in the disorder, none has been tied with certainty to the disease, she says.

Komaroff, at Harvard, calls Jason's study sound, as does CDC's Reeves.

But Reeves wonders if the high rate of chronic fatigue in Chicago ethnic groups would also be found in other urban populations. Furthermore, he notes some differences in the way Jason conducted his study and those the CDC has relied upon in the past. But whether the true number of chronic fatigue sufferers is 500,000 or 800,000, "either way that's a lot of people," he says.



By H. Darr Beiser, USA TODAY

'The height of my career': Terry Hedrick, once a research director in a federal agency, had to retire at 45 when she developed chronic fatigue syndrome.

Despite the urgent need for research, CDC officials recently admitted that the agency had used funding set aside for chronic fatigue syndrome for other purposes.

The Inspector General's Office reports the CDC misappropriated more than \$8 million earmarked for chronic fatigue syndrome.

For Kenney, the charges represent a disturbing trend of trivializing this disease. The CDC's Jeffery Koplan formally apologized to Kenney's group and has vowed that the diversion will not happen again.

For people suffering from chronic fatigue syndrome, the scandal represents a personal blow.

"There's a desperate need for funding," Moore says.