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Chronic Fatigue No Longer Seen as 'Yuppie Flu'

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For decades, people suffering from chronic fatigue syndrome have struggled to convince doctors, employers, friends and even family members that they were not imagining their debilitating symptoms. Skeptics called the illness “yuppie flu” and “shirker syndrome.”

But the syndrome is now finally gaining some official respect. The Centers for Disease Control and Prevention, which in 1999 acknowledged that it had diverted millions of dollars allocated by Congress for chronic fatigue syndrome research to other programs, has released studies that linked the condition to genetic mutations and abnormalities in gene expression involved in key physiological processes. The centers have also sponsored a \$6 million public awareness campaign about the illness. And last month, the C.D.C. released survey data suggesting that the prevalence of the syndrome is far higher than previously thought, although these findings have stirred controversy among patients and scientists. Some scientists and many patients remain highly critical of the C.D.C.'s record on chronic fatigue syndrome, or C.F.S. But nearly everyone now agrees that the syndrome is real.

“People with C.F.S. are as sick and as functionally impaired as someone with AIDS, with breast cancer, with chronic obstructive pulmonary disease,” said Dr. William Reeves, the lead expert on the illness at the C.D.C., who helped expose the centers' misuse of chronic fatigue financing.

Chronic fatigue syndrome was first identified as a distinct entity in the 1980s. (A virtually identical illness had been identified in Britain three decades earlier and called myalgic encephalomyelitis.) The illness causes overwhelming fatigue, sleep disorders and other severe symptoms and afflicts more women than men. No consistent biomarkers have been identified and no treatments have been approved for addressing the underlying causes, although some medications provide symptomatic relief.

Patients say the word “fatigue” does not begin to describe their condition. Donna Flowers of Los Gatos, Calif., a physical therapist and former professional figure skater, said the profound exhaustion was unlike anything she had ever experienced.

“I slept for 12 to 14 hours a day but still felt sleep-deprived,” said Ms. Flowers, 51, who fell ill several years ago after a bout of mononucleosis. “I had what we call ‘brain fog.’ I couldn't think straight, and I could barely read. I couldn't get the energy to go out of the door. I thought I was doomed. I wanted to die.”

Studies have shown that people with the syndrome experience abnormalities in the central and autonomic nervous systems, the immune system, cognitive functions, the stress response pathways and other major biological functions. Researchers believe the illness will ultimately prove to have multiple causes, including genetic predisposition and exposure to microbial agents, toxins and other physical and emotional traumas. Studies have linked the onset of chronic fatigue

syndrome with an acute bout of Lyme disease, Q fever, Ross River virus, parvovirus, mononucleosis and other infectious diseases.

“It’s unlikely that this big cluster of people who fit the symptoms all have the same triggers,” said Kimberly McCleary, president of the Chronic Fatigue and Immune Dysfunction Syndrome Association of America, the advocacy group in charge of the C.D.C.-sponsored awareness campaign. “You’re looking not just at apples and oranges but pineapples, hot dogs and skateboards, too.”

Under the most widely used case definition, a diagnosis of chronic fatigue syndrome requires six months of unexplained fatigue as well as four of eight other persistent symptoms: impaired memory and concentration, sore throat, tender lymph nodes, muscle pain, joint pain, headaches, disturbed sleeping patterns and post-exercise malaise.

The broadness of the definition has led to varying estimates of the syndrome’s prevalence. Based on previous surveys, the C.D.C. has estimated that more than a million Americans have the illness.

Last month, however, the disease control centers reported that a randomized telephone survey in Georgia, using a less restrictive methodology to identify cases, found that about 1 in 40 adults ages 18 to 59 met the diagnostic criteria — an estimate 6 to 10 times higher than previously reported rates.

However, many patients and researchers fear that the expanded prevalence rate could complicate the search for consistent findings across patient cohorts. These critics say the new figures are greatly inflated and include many people who are likely to be suffering not from chronic fatigue syndrome but from psychiatric illnesses.

“There are many, many conditions that are psychological in nature that share symptoms with this illness but do not share much of the underlying biology,” said John Herd, 55, a former medical illustrator and a C.F.S. patient for two decades.

Researchers and patient advocates have faulted other aspects of the C.D.C.’s research. Dr. Jonathan Kerr, a microbiologist and chronic fatigue expert at St. George’s University of London, said the C.D.C.’s gene expression findings last year were “rather meaningless” because they were not confirmed through more advanced laboratory techniques. Kristin Loomis, executive director of the HHV-6 Foundation, a research advocacy group for a form of herpes virus that has been linked to C.F.S., said studying subsets of patients with similar profiles was more likely to generate useful findings than Dr. Reeves’s population-based approach.

Dr. Reeves responded that understanding of the disease and of some newer research technologies is still in its infancy, so methodological disagreements were to be expected. He defended the population-based approach as necessary for obtaining a broad picture and replicable results. “To me, this is the usual scientific dialogue,” he said.

Dr. Jose G. Montoya, a Stanford infectious disease specialist pursuing the kind of research favored by Ms. Loomis, caused a buzz last December when he reported remarkable improvement in 9 out of 12 patients given a powerful antiviral medication, valganciclovir. Dr. Montoya has just begun a randomized controlled trial of the drug, which is approved for other uses.

Dr. Montoya said some cases of the syndrome were caused when an acute infection set off a recurrence of latent infections of Epstein Barr virus and HHV-6, two pathogens that most people are exposed to in childhood. Ms. Flowers, the former figure skater, had high levels of antibodies to both viruses and was one of Dr. Montoya's initial C.F.S. patients.

Six months after starting treatment, Ms. Flowers said, she was able to go snowboarding and take yoga and ballet classes. "Now I pace myself, but I'm probably 75 percent of normal," she said.

Many patients point to another problem with chronic fatigue syndrome: the name itself, which they say trivializes their condition and has discouraged researchers, drug companies and government agencies from taking it seriously. Many patients prefer the older British term, myalgic encephalomyelitis, which means "muscle pain with inflammation of the brain and spinal chord," or a more generic term, myalgic encephalopathy.

"You can change people's attributions of the seriousness of the illness if you have a more medical-sounding name," said Dr. Leonard Jason, a professor of community psychology at DePaul University in Chicago.

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