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OP-ED CONTRIBUTOR

A Case of Chronic Denial

By HILLARY JOHNSON

EARLIER this month, a study published in the journal *Science* [answered](#) a question that medical scientists had been asking since 2006, when they learned of a novel virus found in prostate tumors called xenotropic murine leukemia virus-related virus, or XMRV: Was it a human infection?

XMRV is a gammaretrovirus, one of a family of viruses long-studied in animals but not known to infect people. In animals, these retroviruses can cause horrendous neurological problems, immune deficiency, lymphoma and leukemia. The new study provided overwhelming evidence that XMRV is a human gammaretrovirus — the third human retrovirus (after H.I.V. and human lymphotropic viruses, which cause leukemia and lymphoma). Infection is permanent and, yes, it can spread from person to person (though it is not yet known how the virus is transmitted).

That would have been news enough, but there was more. XMRV had been discovered in people suffering from chronic fatigue syndrome, a malady whose very existence has been a subject of debate for 25 years. For sufferers of this disease, the news has offered enormous hope. Being seriously ill for years, even decades, is nightmarish enough, but patients are also the targets of ridicule and hostility that stem from the perception that it is all in their heads. In the study, 67 percent of the 101 patients with the disease were found to have XMRV in their cells. If further study finds that XMRV actually causes their condition, it may open the door to useful treatments. At least, it will be time to jettison the stigmatizing name chronic fatigue syndrome.

The illness became famous after an outbreak in 1984 around Lake Tahoe, in Nevada. Several hundred patients developed flu-like symptoms like fever, sore throat and headaches that led to neurological problems, including severe memory loss and inability to understand conversation. Most of them were infected with several viruses at once, including cytomegalovirus, Epstein-Barr and human herpesvirus 6. Their doctors were stumped. The Centers for Disease Control and Prevention, the nation's presumed bulwark against emerging infectious diseases, dismissed the epidemic and said the Tahoe doctors "had worked themselves into a frenzy." The sufferers, a C.D.C. investigator told me at the time, were "not normal Americans."

When, by 1987, the supposed hysteria failed to evaporate and indeed continued erupting in other parts the country, the health agency orchestrated a jocular referendum by mail among a handful of academics to come up with a name for it. The group settled on “chronic fatigue syndrome” — the use of “syndrome” rather than “disease” suggested a psychiatric rather than physical origin and would thus discourage public panic and prevent insurers from having to make “chronic disbursements,” as one of the academics joked.

An 11th-hour plea by a nascent patient organization to call the disease by the scientific name used in Britain, myalgic encephalomyelitis, was rejected by the C.D.C. as “overly complicated and too confusing for many nonmedical persons.”

Had the agency done nothing in response to this epidemic, patients would now be better off. The name functioned as a kind of social punishment. Patients were branded malingerers by families, friends, journalists and insurance companies, and were denied medical care. (It’s no coincidence that suicide is among the three leading causes of death among sufferers.) Soon the malady came to be widely considered a personality disorder or something that sufferers brought upon themselves. A recent study financed by the C.D.C. suggested that childhood trauma or sexual abuse, combined with a genetic inability to handle stress, is a key risk factor for chronic fatigue syndrome.

Many people don’t realize how severe this illness can be. It is marked by memory and cognition problems, and physical collapse after any mental or physical exertion. The various co-infections that occur only make matters worse. Many patients are bedridden. And recovery is rare. A significant number of patients have been ill for more than two decades.

Dr. Nancy Klimas, an immunologist at the University of Miami School of Medicine who treats AIDS and chronic fatigue syndrome, [remarked](#) in The Times last week that if given the choice she would prefer to have AIDS: “My H.I.V. patients for the most part are hale and hearty,” she said, noting that billions of dollars have been spent on AIDS research. “Many of my C.F.S. patients, on the other hand, are terribly ill and unable to work or participate in the care of their families.”

Congress has appropriated money for research on chronic fatigue syndrome, too, though in far smaller amounts, but the C.D.C. has seemed unwilling to spend it productively. A decade ago, investigations by the inspector general for the Department of Health and Human Services and what was then called the General Accounting Office [revealed](#) that for years government scientists had been funneling millions meant for research on this disease into other pet projects.

As public health officials focused on psychiatric explanations, the virus apparently spread widely. In the new study, active XMRV infections were found in 3.7 percent of the healthy controls tested. Roughly the same degree of infection in healthy people has been found in the prostate research. If

this is representative of the United States as a whole, then as many as 10 million Americans may carry the retrovirus.

It is estimated that more than a million Americans are seriously ill with the disease. (Not everyone infected with XMRV will necessarily get chronic fatigue syndrome — in the same way that not all of the 1.1 million Americans infected with H.I.V. will get AIDS.)

Hints that a retroviral infection might play a role in chronic fatigue syndrome have been present from the beginning. In 1991, Dr. Elaine DeFreitas, a virologist at the Wistar Institute in Philadelphia, [found](#) retroviral DNA in 80 percent of 30 chronic fatigue patients. The C.D.C. went so far as to try to replicate her effort, but refused to follow her exacting methods for finding the virus. In addition, the centers' blood samples became contaminated, and some people at the agency said that administrators ended the research prematurely. Rather than admit any such failure, the C.D.C. publicly criticized Dr. DeFreitas's findings.

That episode had a chilling effect on other researchers in the field, and the search for the cause was largely abandoned for 20 years.

Now, Judy Mikovits, the retrovirus expert at the Whittemore Peterson Institute, in Reno, Nev., who led the recent study, has revisited the cold case. Not surprisingly, the institute is private, created by the parents of a woman who suffers from chronic fatigue syndrome. But Dr. Mikovits collaborated with scientists at the National Cancer Institute and the Cleveland Clinic.

When she began her work on this disease in 2006, Dr. Mikovits, a 22-year veteran of the National Cancer Institute, knew little about chronic fatigue syndrome. But she was intrigued that an unusually high number of patients being followed by a Nevada doctor were suffering rare lymphomas and leukemias; at least one had died. And she was also impressed that the doctor, Dan Peterson, had built an extraordinary repository of more than 8,000 chronic fatigue syndrome tissue samples going back as far as 1984.

“My hypothesis was, ‘This is a retrovirus,’ and I was going to use that repository to find it,” Dr. Mikovits told me.

What she found was live, or replicating, XMRV in both frozen and fresh blood and plasma, as well as saliva. She has found the virus in samples going back to 1984 and in nearly all the patients who developed cancer. She expects the positivity rate will be close to 100 percent in the disease.

“It’s amazing to me that anyone could look at these patients and not see that this is an infectious disease that has ruined lives,” Dr. Mikovits said. She has also given the disease a properly scientific new name: X-associated neuroimmune disease.

For patients who have been abandoned to quackish theories and harsh ideologies about their illness for 25 years, the dismantling of “chronic fatigue syndrome” can’t come soon enough.

Hillary Johnson is the author of “Osler’s Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic.”

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