

# Delay in Release of Study on Chronic Fatigue Syndrome Prompts an Outcry

Researchers at the [National Institutes of Health](#) and the [Food and Drug Administration](#), citing a need to re-evaluate their data, have delayed publication of a new study believed to provide evidence of a link between [chronic fatigue syndrome](#) and a little-known retrovirus.

The study, already peer-reviewed, was supposed to appear in the prestigious [Proceedings of the National Academy of Sciences](#). The delay has sparked an outcry on blogs and social networking sites among chronic fatigue patients, who are desperate for answers about their debilitating illness and fear that important scientific data are being suppressed.

“A cabal of top government administrators” with a habit of “heavy-handed, anti-science manipulation of peer-reviewed science” ordered the delay, Hillary Johnson, author of a book about the history of chronic fatigue syndrome, alleged on her Web site, [OslersWeb](#).

Federal officials said publication was delayed because the findings contradicted those of the [Centers for Disease Control and Prevention](#), which conducted its own study on chronic fatigue and the retrovirus, known as XMRV. The [C.D.C. study](#), which found no connection, was initially also held up for reassessment because of the discrepancies, but was eventually published on July 1 in the journal *Retrovirology*.

A spokeswoman for the National Institutes of Health declined to comment in detail, but provided a statement from Dr. Harvey Alter, an author of the still-unpublished study and an N.I.H. infectious-disease expert. He said, “My colleagues and I are conducting additional experiments to ensure that the data are accurate and complete,” adding, “Our goal is not speed, but scientific accuracy.”

Word of the findings from the N.I.H. study spread rapidly last month when a Dutch magazine quoted Dr. Alter as saying that his research team had found a high rate of XMRV infection among patients with chronic fatigue syndrome. Dr. Alter reportedly made the statements at a blood safety meeting in Zagreb, Croatia.

Dr. Randy Schekman, editor in chief of the *Proceedings of the National Academy of Sciences*, said last week that he expected the matter to be resolved within weeks, although he would not discuss specifics of the study or the journal’s review of it.

The journal, he added, had been “inundated by e-mails from people with chronic fatigue syndrome begging us to release this paper.”

The debate over XMRV began last fall, when the journal *Science* published a [study reporting that two-thirds of blood samples](#) from 101 chronic fatigue patients showed evidence of infection with the retrovirus, compared with less than 4 percent of 218 healthy controls.

According to the C.D.C., at least one million Americans are believed to have chronic fatigue syndrome, marked by disordered sleep, cognitive problems, headaches, [joint pain](#) and profound exhaustion. The illness has no known cause and has frequently been dismissed by doctors, researchers and the general public as psychosomatic or psychiatric in nature.

Retroviruses, like [H.I.V.](#) and XMRV, store their genetic material as RNA but convert it to DNA to replicate within host cells. Since XMRV was first identified four years ago, several studies have linked it to [prostate cancer](#), although other research has failed to find a link. Whether the retrovirus plays a causal role in this or any disease remains unknown.

The emerging research has caught the attention of the blood bank industry. [Canada recently began barring people with chronic fatigue syndrome from donating blood](#) because of concerns about possible XMRV transmission. The AABB, formerly known as the American Association of Blood Banks, [issued a similar recommendation last month](#).

A confirmed link between chronic fatigue syndrome and XMRV could spur thousands of patients to demand treatment with antiretroviral medications. Although some drugs used to treat the human immunodeficiency virus have demonstrated XMRV-fighting properties in the lab, they have not been clinically tested for this use.

Nonetheless, Dr. Jamie Deckoff-Jones, a physician in Santa Fe, N.M., [has been blogging to an eager audience](#) about the improvements she and her daughter, both given a diagnosis of chronic fatigue syndrome, have experienced while following a regimen of H.I.V. medications.

“I’m taking antiretrovirals in an attempt to save my life,” she explained in an e-mail message. “I don’t have five years to wait around while the scientists and politicians try to figure it out.”

Since the report last year in Science, however, three other published studies, like the new C.D.C. paper, have raised doubts by failing to replicate the findings. The contradictory findings have been attributed to factors like how chronic fatigue cases have been selected and the difficulty in identifying XMRV infection because of a lack of standardized testing protocols.

The Science study was conducted by the [Whittemore Peterson Institute for Neuro-Immune Disease](#), a research center at the [University of Nevada, Reno](#), along with the [National Cancer Institute](#) and the [Cleveland Clinic](#). Annette Whittemore, founder and president of the institute, faulted C.D.C. researchers for historically focusing on stress and other psychological factors as major causes of chronic fatigue syndrome, rather than possible infection.

“They’ve been working on chronic fatigue syndrome since the mid-80s, and yet we still don’t have any answers from the C.D.C.,” said Ms. Whittemore, whose daughter has the illness.

Stephan Monroe, director of the C.D.C.’s division of high-consequence pathogens and pathology, said the agency believed that infectious agents could be one of many possible triggers for the disease but that no pathogen had yet emerged as a “primary cause.”

He said he was not surprised by the current uproar among patients. “This is a very well-informed and highly connected patient and advocacy population, and whenever there’s any new information, it’s circulated widely,” he said.