

# OSLER'S WEB

Inside the Labyrinth of the  
Chronic Fatigue Syndrome  
Epidemic

HILLARY JOHNSON

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INSIDE THE LABYRINTH OF THE  
CHRONIC FATIGUE SYNDROME  
EPIDEMIC

by Hillary Johnson

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Attention to a "mysterious disorder" occurred in the mid-1980s when two physicians from Lake Tahoe began seeing patients with an infectious mononucleosis-like illness that failed to resolve. The patients reported multiple symptoms, including severe fatigue, chills, fever, headaches, sore throat, memory and concentration problems, and insomnia. Epidemiologists from the Centers for Disease Control (CDC) were called to the Lake Tahoe area to help with the investigation of this possible outbreak. *Osler's Web* details the story of Chronic Fatigue Syndrome (CFS) beginning in 1984. The book is based on interviews over a nine-year period, information obtained through the Freedom of Information Act and previously published articles.

The book is almost 750 pages and is organized chronologically by year. The

narrative is easy to read and provides a fascinating tale as the story unfolds. The tale consists of patient descriptions of their symptoms, accounts of meetings between physicians and roadblocks researchers faced to solve this mystery. In the story there are good and evil characters and organizations. Those in white hats are the practicing clinicians in the field, their research scientists and a struggling pharmaceutical company trying to bring a curative drug to market. The evil characters in black hats are those at the National Institutes of Health, Food and Drug Administration and CDC. The story begins as the evil government agencies battle the outside physicians who are struggling to uncover the truth to help patients with this devastating illness. The saga would make a great movie!

The book, written as nonfiction, is filled with numerous errors, making it more like a fictional account reported by an unscientific journalist. Bad science is worse than no science at all, and this book glorifies the poor scientists who make all those great unconfirmed discoveries. *Osler's Web* gives examples of peer reviewed journals refusing to publish key discoveries on CFS made by researchers in the field. Reputable journals, including the *New England Journal of Medicine*, do not reject verifiable studies. Poorly designed research studies (such as the trial of a drug, Ampligen, used to treat CFS patients) were rejected by the *New England Journal of Medicine* because of multiple deficiencies in research methods.

There are more misconceptions. The author, Hillary Johnson compares CFS symptoms with those of AIDS, although there is no evidence that this illness is "AIDS minor or a form of AIDS." The CDC is blamed for discrediting use of the Epstein-Barr virus serology as a test for the illness. Again, there is no evidence that the Epstein-Barr virus plays a role in CFS. In fact, there is presently no test to establish a diagnosis of CFS. Johnson describes the loss of fingerprints as important criteria in the diagnosis. Research has not proven this nor has it been published in a peer reviewed journal. The current diagnosis is symptom-based and relies on each patient's history.

Johnson believes that the name "Chronic Fatigue Syndrome" trivializes the illness. I was involved with the selection of the name as part of the original consensus group. Since the etiology was not known, it was inappropriate to label it postviral fatigue syndrome. Similarly, the evidence for an immune disorder remains controver-

sial, and not all patients with the illness have immune function abnormalities. The name was selected with no intention of trivializing the devastating illness experienced by patients.

In addition, Johnson refers many times to a 1985 article published in the *Annals of Internal Medicine* describing a role for Epstein-Barr virus in CFS. In fact, this article was published in 1987 along with a companion article on the same subject. Johnson writes that the panel members who prepared the CFS case definitions (both the original definition published in 1988 and the current definition published in 1994) consisted of individuals who had not seen any CFS patients, with one exception. This is clearly wrong. A number of authors on the paper had seen many patients with CFS, and the definition was based both on information from the CDC surveillance study as well as their experience.

Johnson cites the beneficial effects of acyclovir treatment for patients with CFS and criticizes one investigator, who, in a carefully controlled trial using acyclovir, found no benefit from the drug compared with placebo. The author does not ask why the clinicians who supported the use of acyclovir have failed to conduct a well-controlled study using the drug. Finally, Johnson is misinformed about the work of the surveillance study group to identify patients with CFS. Patients with laboratory abnormalities or a history that could cause symptoms mimicking CFS were appropriately excluded.

I believe that patients with CFS have a "real illness" which is not a psychosomatic disorder. I have seen hundreds of patients with the illness since the early 1980s. Its frequency depends on the criteria used for the case definition. Good research is needed to better define the pathogenesis of the illness and to learn about the illness using well designed controlled trials to treat patients.

The major strength of *Osler's Web* is that it calls attention to a problem which needs to be carefully studied. CFS is not a new illness, and federal funding is critical to support good scientific research. The CFS support groups have had an invaluable role in calling attention to the problem and the plight of patients with this disorder.

Unfortunately, the book does not succeed in untangling the CFS web. Dr. William Osler, who lived by careful science, would not have wished to be associated with such a poorly conceived, unscientific narrative.