

Hi, XXXXXX--I was a reporter at the SF Chronicle and also have a public health background. I teach reporting about public health at Berkeley, and am in charge of a new double-masters program in public health and journalism:

<http://sph.berkeley.edu/students/degrees/programs/mj-mph.php>

These days I write frequently for the NY Times' health/science section. Most recently, I've done a batch of stories for the newspaper about chronic fatigue syndrome, and in particular about whether the illness is linked to XMRV, a retrovirus (probably not, as it turns out). But there's also a larger, and largely uncovered, story--about the U.S. Centers for Disease Control's disastrous record on chronic fatigue syndrome. The country's leading public health agency has essentially engaged in a kind of 'epidemiologic malpractice' that continues to this day.

This story has been overlooked, I think, because of the stereotype of people with chronic fatigue syndrome, or CFS, as a bunch of whiners and malingerers--when in fact the illness can destroy people's lives and leave them severely disabled, even homebound. And since no one dies and the symptoms are largely non-specific, it's easy for family members, friends, colleagues, doctors, and health officials--not to mention journalists--to dismiss the illness as imaginary, psychosomatic or arising from depression or other emotional problems.

Despite abundant evidence that CFS patients suffer from major immunological and other physiological dysfunctions and from a range of viral infections, the agency has largely ignored these findings to focus on investigating purported psychiatric and stress-related causes--a strategy that has enraged many of the estimated one million people with the illness. (The approach has delighted insurance companies, however; they routinely cite the agency's website in rejecting claims for lab tests, treatments and other CFS-related care.)

Last year the CDC abruptly dismissed the longstanding architect of its CFS program--Dr. William Reeves, a combative and widely disliked epidemiologist--after a sustained revolt against his leadership by virtually the entire CFS scientific, medical and patient community. This battle is clearly laid out in minutes and other documents from a key Health and Human Services advisory committee. Although Dr. Reeves' transfer to another CDC department was clearly an attempt to alleviate the tensions, the agency's focus does not appear to have changed in the year since. Chronic fatigue syndrome patients and leading researchers remain deeply unhappy with the agency.

In fact, the first major CDC misstep actually occurred 23 years ago, when the agency published its initial report about chronic fatigue syndrome and saddled it with one of the worst names in disease-naming history--even though an identical illness had already been called 'myalgic encephalomyelitis' in the U.K. and recognized by the WHO since the 1960s. Patients generally despise the name since it reinforces the popular notion that they are non-stop complainers; they have long blamed the CDC for inflicting it on them and are aggressively advocating a name-change.

Anyway...let me know if this holds any interest. I could pull the story together fairly quickly, since I've already done most of the reporting.

Thanks much--David T.