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Below is the long version of [PANDORA's](#) op-ed

Funding for Chronic Fatigue Syndrome Should Be Increased

On June 8th, 2007, the Centers for Disease Control (CDC) announced stunning new prevalence figures for chronic fatigue syndrome (CFS): 6 to 10 times more adults in the U.S. struggle with this disease than previously believed, numbering in the millions (www.pophealthmetrics.com). An earlier CDC study estimating 400,000 in 1999 used methods that left many sufferers uncounted. Though concerns remain about the CDC's methodology, the new numbers leave no doubt that CFS is a major public health problem deserving serious attention from federal, state and local agencies.

Even under the old prevalence figures, the CDC estimated that CFS cost the U.S. economy \$9.1 billion a year in lost income and productivity, with patients often being more impaired than people with multiple sclerosis, AIDS, or end-stage renal failure.

This is a time of increased hope for those with CFS and other neuroendocrine/immune disorders (fibromyalgia and Gulf War illnesses), as cutting-edge research advances. The International Association for CFS recently held its 8th annual medical conference in Fort Lauderdale, where researchers and physicians from 21 countries announced ground-breaking studies noting that individuals with CFS have impaired brain/neurological and sleep functions, severely weakened neuroendocrine and immune systems, as well as autonomic system dysfunctions.

The new prevalence numbers emphasize the painfully inadequate resources devoted to CFS. Though CFS sufferers in Florida are estimated in the tens of thousands, leading CFS researcher and clinician Dr. Nancy Klimas of the University of Miami is currently the only CFS specialist for the entire state. Her multidisciplinary research team needs greater financial support and expansion of their clinic facilities.

Since the mid-80s, when this current epidemic first appeared across the U.S., millions of seriously ill people have been unable to find needed care and support. Although 20 years of grassroots advocacy has brought federal attention to this illness, federal support of CFS research is only a fraction of what it should be. Federal funding for CFS research, from both the CDC and National Institutes of Health (NIH), remains shamefully low. Of some 120 diseases the NIH funds, CFS ranks in the bottom dozen, although the illness affects far more citizens than lung cancer and HIV/AIDS combined.

Since young scientists are attracted to research fields receiving generous NIH funding, inadequate funding is a serious threat to ongoing research. Without the commitment of young investigators, the search for accurate diagnostics and effective treatments will be slowed and possibly cease. Limited funding also precludes the larger, more rigorous studies needed to bring greater credibility to research.

The media and the public must be continuously informed about CFS. We need to spur our legislators to increase CFS funding. We need national training programs so physicians and other healthcare workers can recognize CFS and apply a proper standard of care. We need public policy that funds services for those disabled by CFS.

We need to heed the lesson of the CFS debacle: A disease long dismissed as nonexistent or "all in the head" turns out to be all too real, a multi-organ system ailment, and far more common than the CDC originally estimated. Both the public and medical community should note: neuroendocrine-immune illnesses are on the rise. The medical community must be prepared to respond. There is a great deal to learn about the brain, the endocrine and immune systems, and how environmental pollutants or subtle biochemical changes impact health. Because CFS research raises questions basic to the understanding of human health and will unlock the mysteries of other chronic illnesses, this research deserves a dramatic increase in federal funding.

Dorothy Wall is author of *Encounters with the Invisible: Unseen Illness, Controversy, and Chronic Fatigue Syndrome* (Southern Methodist University Press). For more information: www.dorothywall.com

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[Click here for the South Florida Sun-Sentinel shortened version of PANDORA's op-ed published on July 12, 2007.](#)

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