

# The CFIDS Association of America

*Working to conquer chronic fatigue and immune dysfunction syndrome*

March 31, 2008

Honorable Harry Reid  
Majority Leader  
United States Senate  
US Capitol, Room S-221  
Washington, D.C. 20510

Dear Senator Reid:

On behalf of the Chronic Fatigue Syndrome (CFS) patient community, I write to convey our serious concerns regarding the status of the CFS program at the Centers for Disease Control and Prevention (CDC) and request your attention and assistance.

The restoration of \$12.9 million to the CFS program between FY2000-2005 represented an era of enhanced fiscal accountability and transparency in the program, and most importantly, initiated a period of great growth and productivity in research and marketing efforts. At an April 20, 2006 media briefing, CDC Director Dr. Julie Gerberding, announced publication of 14 peer-reviewed articles about CFS in a special issue of *Pharmacogenomics*, referring to the program as a model for other complex public health issues faced by CDC. Five months later, in November 2006, Dr. Gerberding led a press conference announcing the first-ever public awareness campaign for CDC and media outlets around the world carried the message, "CDC: CFS real, brutal." (UPI, Nov. 3, 2006). At the time, we believed that the CDC was poised to carry this momentum toward important advances in diagnosis, care and prevention.

However, events since the press conference have led us to seek your assistance in clarifying the direction of the program. Here are some of our major concerns: The number of CFS publications generated by the CDC research group in 2007 was far fewer than would be expected given large studies that have already generated massive data sets for analysis. The single paper published on a multi-year study of CFS in Georgia in June 2007 has yielded a new estimate of the prevalence of CFS, increasing it from one million Americans to more than 4 million Americans. However, there is continued debate within the agency about this estimate, resulting in several different published figures for CFS prevalence by CDC. The program has severely curtailed laboratory studies and external collaborations, other than those conducted with Emory University. With great regret, the CFIDS Association of America elected not to continue as the CFS program's contractor for provider education activities in August 2007, citing our concerns about the direction of the research program. A study conducted with the U.S. Army of fatigued recruits was suddenly halted due to problems with study conduct, according to an article published in the *Atlanta Journal-Constitution* on Sept. 3, 2007.

In November 2007, the DHHS CFS Advisory Committee unanimously approved a detailed recommendation to Secretary Michael O. Leavitt that CDC restructure its efforts on CFS to reflect broader expertise, greater accountability, stronger emphasis on extramural

collaborations and expanded studies of biomarkers and therapeutic approaches to CFS. This recommendation echoed suggestions made by a Blue Ribbon Panel convened in January 2007 by the Coordinating Center for Infectious Diseases to help determine where in the new CDC organizational structure the CFS program best fit.

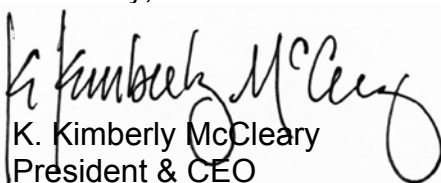
In summary, we are concerned that the period of great productivity and promise has given way to a lack of strategic focus, accountability and transparency. We seek your assistance in urging CDC to provide the following information:

- Implementation status of the recommendations of the Blue Ribbon Panel and the DHHS CFS Advisory Committee
- Consideration of an immediate peer-review of the CFS program to assess past performance, current studies and future plans
- Presentation of a detailed financial, personnel and programmatic report for FY2005-2007 that reflects the following areas and include an update on this report each year on the Congressional Justification for the budget:
  - Surveillance and epidemiology
  - Clinical assessment and evaluation
  - Objective diagnosis and pathophysiology
  - Treatment and intervention
  - Provider education and public marketing efforts
- A deadline, under existing data-sharing policies, for making the rich data sets accumulated by CDC through the community-based and clinical studies of CFS available to other research groups as a means of expanding the opportunity for discovery with little added cost to the agency.

Senator Reid, we deeply appreciate your tireless advocacy in support of the CFS patient community and we know that you are committed to assisting us in fulfilling the promise of better diagnostics and therapeutic approaches to reduce the significant burden of illness posed by CFS. Your immediate assistance in helping us determine the state of the CFS program at CDC and restore its promise would be incredibly important and hopefully will lead to improved transparency, accountability and performance.

Thank you again for your attention to these matters and for your unwavering support.

Sincerely,



K. Kimberly McCleary  
President & CEO

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