



Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

August 4, 2009

Ms. K. Kimberly McCleary
President and Chief Executive Officer
The CFIDS Association of America
P.O. Box 220398
Charlotte, North Carolina 28222

Dear Ms. McCleary:

Thank you for your letter with your recommendations on the strategic research plan for the Chronic Fatigue Syndrome (CFS) program at the Centers for Disease Control and Prevention (CDC).

CDC's CFS peer-reviewed research program uses tools and approaches that allow reproducible data and standard protocols to optimize results that will stand the scrutiny required of science-based programs and be worthy of the CFS patients we strive to help. As you are well aware, CDC is currently developing a strategic research plan that will drive the program's research, prevention, and control activities for the next five years. In developing and revising this plan, CDC is considering diverse input from the November 2008 peer review of its CFS research program, the April 2009 CFS stakeholders' meeting, the May 2009 Department of Health and Human Services (HHS) Chronic Fatigue Syndrome Advisory Committee (CFSAC), and other contributions received from members of the public, the CFS research community, and the CFIDS Association of America. It is our sincere desire that with an increasing emphasis on translational research that involves the design, implementation, and evaluation of interventions, that we will reduce the morbidity associated with CFS and improve the quality of life of persons with the illness.

While CDC is awaiting formal guidance from HHS regarding the CFSAC recommendations that have been transmitted to HHS Secretary Sebelius, internal discussions are underway to discuss next steps toward finalizing the next draft of the plan. Let me assure you that the issues you raise in your letter are being carefully considered, and I will briefly address your recommendations here.

1. Align CDC CFS program with necessary agency leadership and projected resources.

CDC's CFS research program integrates multidisciplinary public health research and education activities to establish intervention and research strategies to detect, control, and prevent CFS. A major focus of the program is to provide evidence-based information to the public and providers to assure that it addresses their current concerns and is in a readily accessible format. CDC will continue to evaluate outcomes associated with the dissemination of public health information through its partnerships formed with healthcare providers participating in the patient registry and engage state and local health departments in the development of a CFS toolkit and its dissemination to public health agencies. Such existing and new collaborators, including pharmaceutical companies, will also aid in clinical behavioral interventions studies and pharmacologic trials targeting pathophysiologic pathways involved in CFS.

2. Leverage unique data assets to support global public health and research efforts.

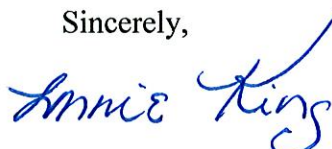
CDC shares this philosophy and is committed to making our research data available to the public but must also comply with existing law and policy with regard to sharing and releasing such data. As you are aware, these large data sets typically have personal information that impact on IRB issues and to redact the identifiers would require substantial resources. CDC will continue to work with the Office of Science and Technology Policy, HHS, and others to develop internal working policies and procedures to implement these goals in a timely fashion.

3. Support clinical research network.

CDC hopes to develop a framework for collaboration among the leading CFS researchers by including workshops and international research networks as part of its five-year strategic research plan. Proposed activities will focus on developing an international consensus regarding the clinical management of CFS and the diagnosis of CFS in clinical and research settings, as well as establishing an international CFS research network to encourage data sharing.

Please be assured that CDC's committed to continued success in its CFS research endeavors and to establishing new levels of partnership in advancing an integrated public health strategy for CFS. Thank you for your interest in CDC and in CFS and for your suggestions.

Sincerely,



Lonnie King, DVM
Director

National Center for Zoonotic, Vector-Borne,
and Enteric Diseases