

# The CFIDS Association of America

*Working to conquer chronic fatigue and immune dysfunction syndrome*

Dr. Stephen Monroe, Director  
Division of Viral and Rickettsial Diseases  
U.S. Centers for Disease Control and Prevention  
Atlanta, Georgia 30333

February 10, 2009

Dear Dr. Monroe,

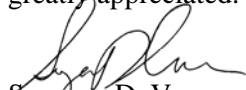
The CFIDS Association of America has successfully funded a CFS research network after reviewing 24 full proposals and selecting six that were highly meritorious scientifically and strategically. I will coordinate the investigators leading these six studies as a research network, collecting standard epidemiologic, clinical and laboratory data on all subjects. This will serve as a beginning framework so that we can expand this network to other investigators over time.

The data amassed by the CDC CFS Research program is a valuable resource that must be released and shared in accordance with the CDC/ATSDR Policy on Releasing and Sharing Data and the President's memorandum dated January 21, 2009 that directs all executive agencies to "take appropriate action, consistent with law and policy, to disclose information rapidly in forms that the public can readily find and use." By releasing the data in accordance with these policies, you are ensuring it will be used to its full potential, that work is not duplicated, and that funds are not spent unnecessarily. In addition, as a field, we will increase the efficiency and evidence-based nature of CFS research by: 1) using standard instruments to record key symptoms, measure functional impairment, and identify comorbid or exclusionary conditions; 2) using standard methods of sample collection, handling, storage and standardized assay methodologies in order to minimize sources of variation in laboratory parameters; and, 3) validating constructs and biomarkers.

The Association requests that you make available all the epidemiologic, clinical and laboratory data (including gene expression, proteomic and genetic data where applicable) from studies conducted by the CFS Research program since the 1984 investigations including the Incline Village outbreak investigation, Four Cities Surveillance, Atlanta Case Control, Wichita Longitudinal, Wichita Clinical, Georgia Survey, and the ongoing Georgia GCRC study. The Association requests that you release the above noted data without restrictions for public use as a subject-oriented relational database. This database must maintain relation of all data variables to study subject while adhering to OMB regulations on data quality. As you know, CDC has data repository and the data dissemination resources to enable fulfillment of this request.

The Association requests that all gene expression data collected to date by the CFS research program be submitted to the NCBI Gene Expression Omnibus including, but not limited to, gene expression results from the Atlanta Case Control, Wichita Longitudinal, Wichita Clinical, DIOS Post-Infection Fatigue, Interferon Alpha, TSST in Healthy Men and the Georgia GCRC. Single nucleotide polymorphism data from Wichita Clinical, Georgia Survey, Georgia Follow-up and the Georgia GCRC should be submitted to the NCBI dbSNP. The CDC CFS research program should identify or create a suitable database for deposition and public use of the plasma proteome data generated from the Wichita Clinical study.

The use of a single contractor, Abt Associates, for all of these studies should greatly facilitate the compilation and release of these various datasets. The courtesy of a reply to this request by February 27, 2009 would be greatly appreciated. Thank you in advance for your cooperation.



Suzanne D. Vernon, PhD  
Scientific Director

cc: Michael Miller, Associate Director for Science, NCZVED  
William C. Reeves, Chief, CVDB