

The CFIDS Association of America offers the following Recommendations for Fiscal Year 2005 Appropriations Committee Report Language:

Secretary for Health

The Committee is pleased that the Department's Chronic Fatigue Syndrome Advisory Committee (CFSAC) is meeting regularly. This advisory committee serves an important role in fostering collaboration between federal agencies, scientists and CFS advocates to promote research and education on CFS and meet the social service needs of persons with CFS. The Committee awaits the Secretary's response to the CFSAC's recommendations dated August 23, 2005.

Centers for Disease Control and Prevention

The Committee recognizes that CDC has developed the most comprehensive CFS program in the nation, conducting community-based studies, clinical and laboratory research and education through collaborations with academic institutions and non-governmental organizations. The Committee directs CDC to provide sufficient resources to maintain the high caliber of this program. The Committee is very interested in CDC efforts to identify biomarkers using genomic and proteomics technology, to educate health care providers to appropriately diagnose and treat CFS, and to better inform the public about the severity and magnitude of this condition. Within 60 days of the passage of this Bill, CDC will report to the Committee a detailed accounting for the \$12.9 million restored to the CFS program in response to the

National Institutes of Health

The Committee is deeply concerned that NIH has failed to expand research on CFS and that a June 2003 commitment to issue an RFA has not yet been fulfilled. The RFA should emphasize multi-disciplinary studies to understand the cause and progression of CFS in adults and children as well as identify diagnostic markers and effective treatments. The Committee is also concerned about NIH's apparent inability to appropriately document the scope of its CFS research portfolio and that reports provided in response to Congressional requests have included grants unrelated to CFS, thus artificially inflating the total dollars awarded for CFS research. It is essential that NIH improve its methods of accounting for disease-specific research and that such financial accountability be made a priority to achieve. Within 60 days of passage of this Bill NIH will report the following information about each grant relating to CFS: the title, principal investigator, research institution, annual funding amount and funding institute for FY01, FY02, FY03 and FY04. Additionally, the NIH will report intramural investigations that relate to CFS.

Health Resources and Services Administration

CFS patients' most crucial need is for effective, compassionate medical care. Through its demonstration grants program, HRSA has experience in piloting new, efficient ways of delivering health care services to those with emerging illnesses. The Committee directs HRSA to provide demonstration grants to develop model CFS clinical centers with the goal of delivering effective, multidisciplinary clinical care to persons with CFS.

Department of Education

The Committee asks that the National Institute on Disability and Rehabilitation Research maintain recognition of CFS as an unmet area of research. The Committee encourages NIDRR to continue to pursue CFS-related research proposals through its investigator-initiated and other grants programs.

The Committee is concerned about reports that students with CFS are not being provided appropriate educational accommodations by their local school districts and instructs the Department to take steps to inform educators about CFS and the special educational needs often required by students with CFS.

Social Security Administration

The Committee encourages SSA officials to educate adjudicators at all levels about the functional impact of CFS and the application of the April 1999 CFS ruling (99-2p) to ensure that adjudicators remain up-to-date on the evaluation of disability imposed by this condition. The Committee encourages SSA to continue examining obstacles to benefits for persons with CFS, to assess the impact of the ruling on disabled CFS patients' access to benefits, and to keep medical information updated throughout all levels of the application and review process.

Please help us achieve our mission of conquering CFS by supporting these requests through the FY'05 Appropriations process.

If you would like this language sent to you electronically (by e-mail or on computer diskette), please contact Sue Peschin at The Sheridan Group, telephone: 202-628-7770, e-mail: speschin@sheridangroupdc.com.