

The CFIDS Association of America offers the following recommendations for Fiscal Year 2006 Labor/HHS Appropriations Committee Report Language:

Secretary for Health

The Committee is pleased that the Department's Chronic Fatigue Syndrome Advisory Committee (CFSAC) has been meeting quarterly. This advisory committee serves an important role in setting priorities for federal research and education programs related to chronic fatigue syndrome (CFS) and in keeping the Department abreast of the needs of persons with CFS. The Committee awaits the Secretary's written response to the CFSAC's recommendations dated August 23, 2004.

Centers for Disease Control and Prevention

With near-completion of the restoration of \$12.9 million to the Chronic Fatigue Syndrome research program in response to a report from the Inspector General dated May 12, 1999, the Committee commends CDC for developing a comprehensive CFS program. The Committee directs CDC to provide sufficient resources to sustain efforts to identify biomarkers for CFS, educate health care providers about the diagnosis and treatment of CFS, and better inform the public about it to aid early detection and improve patient care. Within 60 days of the passage of this Bill, CDC is directed to provide to the Committee a detailed accounting of how the \$12.9 million in restored funding has been used.

National Institutes of Health

The Committee is deeply concerned that NIH has failed to expand research on chronic fatigue syndrome (CFS) and that a June 2003 commitment to issue a Request for Applications (RFA) on CFS has not yet been fulfilled. The RFA should emphasize multi-disciplinary studies to understand the cause and progression of CFS in adults and children, identify diagnostic markers and develop effective treatment. The Committee strongly supports the DHHS CFS Advisory Committee's recommendation to establish five Centers of Excellence within the United States that would effectively utilize state of the art knowledge concerning the diagnosis, clinical management, treatment and clinical research of persons with CFS. These Centers should be modeled after the existing Centers of Excellence program with funding in the amount recommended by the advisory committee.

The Committee is deeply troubled that a CFS funding report for FY99-03 issued in response to Congressional requests included amounts for grants unrelated to CFS, thus artificially inflating the total dollars awarded for CFS research. CFS is just one condition for which this has been a problem. It is imperative that NIH improve its methods of accounting for disease-specific research, consistent with recommendations made by the NIH's Council of Public Representatives and the Institute of Medicine's 2003 report for increased transparency and accountability. The Committee directs the NIH to issue, within 90 days of passage of this Bill, a Request for Applications for CFS research with funding sufficient to support at least 8 new studies. The Committee also directs the NIH to report to the Committee on the numbers of CFS-specific grant applications received and funded since FY00 and to submit its plans for significantly improving methods to accurately track and report disease-specific funding.

Due to the many structural problems that arise with multi-disciplinary research across Institutes, the Committee supports the creation of an Office of Trans-NIH Initiatives housed under the Office of the Director's program coordination activities. This Office would centralize information about research initiatives that involve multiple institutes and centers, including workshop reports and recommendations from the community to the NIH, implementation plans and funding opportunities. This office would also be charged with disease-specific financial accounting for research programs that cut across Institutes and would release an annual report to the public.

Health Resources and Services Administration

CFS patients' most crucial need is for effective, compassionate medical care. Through its demonstration grants program, HRSA has piloted effective 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 that results from this condition. The Committee encourages SSA to examine obstacles to benefits for persons with CFS and to keep medical information updated throughout all levels of the application and review process.

Supporting documentation for these requests is available upon request. Please help us achieve our mission of conquering CFS by supporting these requests through the FY06 appropriations process.

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