

The CFIDS Association of America's Recommendations for Fiscal Year 2007 Appropriations Committee Report Language:

SECRETARY FOR HEALTH

The Committee is concerned that the Secretary has not provided a written response to the Department's Chronic Fatigue Syndrome Advisory Committee (CFSAC) recommendations dated August 23, 2004. The CFSAC helps set priorities for federal research and education programs related to chronic fatigue syndrome (CFS) and keeps the Department abreast of the needs of persons with CFS. The Committee directs the Secretary to respond to the committee within 30 days of enactment of this bill and to provide a copy of the response to this committee. The Committee is also concerned about the lapse in the CFSAC's quarterly meeting schedule and that it took the Department almost one year to appoint new members to replace the 5 CFSAC appointees whose terms expired in September 2005. The Committee directs the Department to ensure a timely nomination and appointment process to replace the 6 CFSAC members whose terms will expire in 2006 and to ensure that the appointment process does not disrupt the committee's schedule of quarterly meetings. In addition, the Committee directs the Secretary to renew the charter and fund the CFSAC by September 5 when the charter is due to expire, so that CFSAC can continue its crucial work.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

With the full 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 that now leads CFS research efforts worldwide. We are greatly encouraged and impressed by the commitment of the CFS research team and the exciting progress it is making in understanding the pathophysiology of CFS. The Committee directs CDC to provide sufficient resources to sustain this leadership and to protect the progress made. The Committee is also concerned that the CDC restructuring not undermine this momentum. Within 60 days of the passage of this Bill, CDC will provide to the Committee a detailed accounting of how the \$12.9 million in restored funding has been used and a report on how the CDC restructuring will affect CFS research. The Committee commends the CDC for its work on the joint CDC/CFIDS Association of America national public education and awareness campaign and recommends continuing this campaign beyond the end of FY07.

NATIONAL INSTITUTES OF HEALTH (NIH)

The Committee commends the NIH for the July 14, 2005 Request for Applications (RFA) on CFS. The Committee directs that this RFA yield a true increase in NIH research on CFS. The Committee 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 range of \$1.5 million per center per year for five years."

The Committee remains 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. The Committee is greatly concerned about NIH's

lack of transparency. 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 from the NIH's Council of Public Representatives and the Institute of Medicine's 2003 report, "Enhancing the Vitality of the NIH: Organizational Changes to Meet New Challenges." Within 60 days of passage of this Bill, NIH will report to the Committee on the number of CFS-specific grant applications received and funded for FY05 and submit its plans for significantly improving methods to accurately track and report disease-specific funding.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

The Committee directs HRSA to utilize materials developed under contract to the CDC for its public and provider education activities about CFS in trainings for health care professionals to improve their ability to diagnose and manage CFS.

The Committee directs HRSA to offer demonstration grants to develop models of delivering effective multidisciplinary clinical care to persons with CFS.

DEPARTMENT OF EDUCATION

The Committee commends the National Institute on Disability and Rehabilitation Research for recognizing 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 that students with CFS are not being provided appropriate educational accommodations by local school districts and instructs the Department to help inform educators about CFS and the special educational needs often required by students with CFS, utilizing materials developed under contract to the CDC for its public and provider education activities about CFS.

SOCIAL SECURITY ADMINISTRATION

The Committee encourages SSA officials to provide training to adjudicators at all levels about the functional impact of CFS and the application of the CFS policy ruling (99-2p), utilizing materials developed under contract to the CDC for its public and provider education activities about CFS. 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 FY07 appropriations process.

For additional information, contact The CFIDS Association of America 704-365-2343 or The Sheridan Group 202-628-7770