

## **CFIDS Association of America Congressional Requests FY2008**

The CFIDS Association asks Congress to direct the **Department of Health and Human Services**, Office of the Secretary to prioritize strategies to address the low rate of diagnosis of CFS, lack of defined standards of medical care for CFS patients and the stagnation in research funding by CDC and NIH in spite of progress being demonstrated in the field.

The CFIDS Association asks Congress to express appreciation for the **National Institutes of Health** (NIH), Office of Research on Women's Health for its leadership on CFS research, particularly the coordination of the Request for Applications that culminated in the October 30, 2006 announcement of 7 new awards for CFS research. Congress should direct NIH to utilize the annual meeting of investigators funded under this initiative to stimulate new research initiatives and build multicenter collaborations that foster success under the Director's Roadmap Initiative. Congress should further direct NIH to develop an intramural CFS research program and to implement the recommendation made by the CFS Advisory Committee 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." Congress should require that within 60 days of passage of the FY08 appropriations bill, that NIH report on how it will move forward on this recommendation and how it will address the erosion of NIH funding for CFS research. It should also remind NIH that it awaits the revised report on funding requested in the FY07 Appropriations Report, regarding the refined coding instructions for appropriately classifying CFS grants and insist that this be a priority for the newly established Office of Portfolio Analysis and Strategic Initiatives (OPASI).

The CFIDS Association asks Congress to commend the **Centers for Disease Control and Prevention** (CDC) for launching the first national CFS awareness campaign and the heightened attention being generated by these communications efforts conducted in collaboration with the CFIDS Association of America. In light of success so far, Congress should state that contract administration related to this campaign should not impede the progress nor slow precious momentum achieved so far in getting valuable information to the public and medical community. The Association asks Congress to acknowledge the work of the CDC's CFS research program, its systems biology approach to CFS and its global leadership. Congress should also recognize that this prominence and progress is jeopardized by the severe funding cuts reported for this program and express concern that funds are dropping even as CDC's own research indicates that the prevalence of CFS may be higher than previously documented, intensifying the need for expanded study and attention. The Association asks that Congress express concern that in FY07, report language provided \$1,000,000 over the budget request to protect the progress being made; however spending for CFS research for FY06 is estimated to reflect a 50% drop compared to the final spending figure for FY05. Congress should insist that CDC restore funding to the FY05 level of \$9 million and provide additional support to continue the effective public awareness campaign. Finally, Congress should indicate that it awaits the report from CDC on how the organizational restructuring will impact the CFS program as well as a report on how CDC will address emerging evidence that human herpesvirus 6A and Epstein-Barr virus may play a role in CFS, perhaps as causative agents.

The CFIDS Association asks Congress to inform the **Health Resources and Services Administration** (HRSA) that the most crucial need for individuals suffering from chronic fatigue syndrome (CFS) is effective, compassionate medical care. Given HRSA's experience in piloting effective ways of delivering health care services to underserved populations and the statistic from CDC that fewer than 20% of patients with CFS have been diagnosed by a health care

professional, Congress should encourage HRSA to announce a demonstration grant program to develop models for CFS clinical care with the goal of improving the diagnosis and management of individuals with CFS throughout our country. Congress should state that within 60 days of the passage of this bill, it requests a report from HRSA on how the needs of this population will be better met.

CDC researchers have reported that CFS is as disabling as chronic obstructive pulmonary disease, end-stage renal failure, and multiple sclerosis. In light of this finding, the CFIDS Association asks Congress to encourage **Social Security Administration** officials to continue the education of adjudicators at all levels about the functional impact of CFS to ensure that they remain up to date on the appropriate evaluation of disability that results from this condition. Congress should ask that within 60 days of the passage of this bill, SSA deliver a report on these ongoing educational activities as well any plans to update the existing policy ruling on CFS, SSR 99-2p.

The CFIDS Association asks Congress to request that the National Institute on Disability and Rehabilitation Research within the **Department of Education** continue to pursue CFS-related research proposals through its investigator-initiated and other grants programs, including sponsoring studies that will illuminate the nature of disability in CFS, particularly the predominant feature of post-exertional relapse, as well as strategies to support the improved function and rehabilitation of CFS patients.

**K. Kimberly McCleary**  
President & CEO  
The CFIDS Association of America  
6827 Fairview Road, Suite A  
Charlotte, NC 28270  
Fax: 704-365-9755