

# The CFIDS Association of America

*Working to make CFS widely understood, diagnosable, curable and preventable*

**Note:** The Labor, HHS, and Education and related agencies bill constitutes the largest of the non-defense Federal appropriations bills being considered by Congress this year.

**U.S. Senate Report 111-066**  
**DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION,**  
**AND RELATED AGENCIES APPROPRIATION BILL**  
**Fiscal Year 2010**  
**(Ordered to Be Printed August 4, 2009)**

## NATIONAL INSTITUTES OF HEALTH (NIH)

*Office of the Director, Office of Research on Women's Health [ORWH]*

*Chronic Fatigue Syndrome [CFS]* - The Committee urges the ORWH to strengthen the network of investigators funded under the fiscal year 2007 CFS neuroimmune research initiative by stimulating new research initiatives and building multicenter collaborations. The Committee again urges the NIH to establish an intramural CFS research program with relevant areas of scientific expertise to study disease pathophysiology, identify biomarkers, objective diagnostic tools and better therapeutic approaches. The Committee urges the NIH to ensure that study sections responsible for reviewing grants on CFS include experts who are qualified in the appropriate disciplines.

*Overlapping Chronic Disorders* - The Committee notes that millions of Americans suffer with one or more of the following chronic disorders: chronic fatigue syndrome, endometriosis, fibromyalgia, headache, interstitial cystitis, irritable bowel syndrome, temporomandibular joint and muscle disorders and vulvodynia. A growing body of evidence demonstrates that these conditions frequently co-exist or overlap, yet all are poorly understood. Progress in treating these prevalent, life-altering disorders has been hindered by their complex genetics and heterogeneous etiologies; however, studying related or clinically overlapping chronic conditions can yield unique biological insight into the mechanisms underlying common disease. The Committee calls upon the Director to coordinate, with all relevant institutes and centers, a trans-NIH research initiative in fiscal year 2010 that will support studies aimed at identifying common etiological pathways, with the goal of identifying potential therapeutic targets. The Committee also requests that the Director hold a conference in fiscal year 2010 that will bring together a wide range of basic and clinical researchers from multiple specialties, as well as professional and patient advocacy organizations, to present and discuss the latest scientific discoveries and develop future research recommendations. The Committee requests an update on progress made in this area in the fiscal year 2011 congressional budget justification.

*National Institute on Dental and Craniofacial Research (NIDCR):*

*Temporomandibular Joint Disorder [TMJD]*- The Committee appreciates that progress has been made in understanding some genetic and gender differences in sensitivity to pain, the role of hormones in modulating pain responses, and the unique anatomical and musculoskeletal characteristics of the temporomandibular joint. Similarly, the Committee looks forward to the results of the current prospective study exploring risk factors for the onset of TMJD. However, minimal progress has been made in understanding the causes of TMJD and mechanisms that might explain the presence of many co-morbid conditions with TMJD that are also associated with pain, such as chronic headache, vulvodynia, irritable bowel syndrome, interstitial cystitis, chronic fatigue and immune dysfunction syndrome, fibromyalgia and generalized pain syndromes. Resolution of TMJD

problems is further hampered by inadequate diagnostics, ineffective and even harmful treatments, and the failure to develop effective medications to treat this and other chronic pain conditions. Therefore, the Committee requests the NIDCR to take the lead in developing a comprehensive 5-year TMJD research plan that articulates the strategies and goals necessary to resolve the issues that have plagued TMJD studies over the decades. The plan should include research to develop definitive diagnostic criteria; support an updated epidemiology, including a count of co-morbid conditions; examine genetic and other factors that increase risk for TMJD; and support endocrine, immune and nervous system research on pain mechanisms and treatments. The plan's research goals should incorporate the appropriate mix of basic, clinical and translational science, recruitment of scientists from the pertinent disciplines, and meaningful training programs to enlarge the pool of investigators and indicate what funding mechanisms should be employed.

## **U.S. CENTERS FOR DISEASE CONTROL & PREVENTION (CDC)**

### *Zoonotic, Vector Borne, and Enteric Diseases*

The Committee directs the CDC to include in its annual budget justification an itemized expenditure of funds for each Chronic Fatigue Syndrome [CFS] research project or activity in the following five functional expense categories: surveillance and epidemiology; clinical assessment and evaluation; objective diagnosis and pathophysiology; treatment and intervention; and education, including the CFS marketing campaign and healthcare provider education. The justification should include a breakdown of intramural and extramural spending and should reflect funding mechanisms used for extramural support, such as contracts, cooperative agreements and grants.

The Committee recognizes that the CDC has accumulated a vast amount of research data related to CFS. This data has great potential to facilitate continuing research. The Committee directs the CDC to report to the Committee by May 1, 2010 on the possibility of and barriers to making this data public in a way that preserves the privacy of research participants. The Committee feels strongly that scientists working on CFS would benefit from access to the epidemiologic, clinical and laboratory data from studies conducted by the CFS research program.