

# The CFIDS Association of America

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

WRITTEN STATEMENT TO THE  
DEPARTMENT OF HEALTH & HUMAN SERVICES  
CHRONIC FATIGUE SYNDROME ADVISORY COMMITTEE  
SUBMITTED MAY 22,2009

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On behalf of the CFIDS Association of America, the largest and most active organization working to make chronic fatigue syndrome (CFS) widely understood, diagnosable, curable and preventable, please accept this written statement for the May 27-28,2009 meeting of the CFS Advisory Committee (CFSAC).

- CFS is a condition of immense magnitude and enormous public burden as measured by its:
- Prevalence - There are up to 4 million cases among adults, adolescents and children in the U.S. alone.
  - Duration - Recovery definitions and rates vary, but few people fully and permanently recover to experience complete symptom remission.
  - Disability - The 1994 definition for CFS requires that the symptoms impose "significant reduction in previous levels of activity"; CDC estimates that at least 25 percent of CFS patients are fully disabled
  - Economic impact - The direct and indirect costs of CFS have been estimated by researcher at DePaul University to be \$17-25 billion per year; CDC has estimated the annual cost of lost productivity due to CFS to be \$9 billion.
  - Lack of diagnostic markers and/or tests - Diagnosis is presently made by excluding other possible causes of symptoms, a process that can be lengthy and costly, especially to individuals who do not have insurance coverage or local access to health care services.
  - Lack of effective treatment(s) - In the absence of a known cause or fully defined pathophysiology, the aim of treatment is to relieve symptoms, improve function and enhance quality of life. Health care professionals are not adequately trained to manage CFS and patients often must coordinate care between providers, if they find knowledgeable care at all.
  - Social stigma - Lack of broad understanding and recognition of the severity and impact of CFS contribute to feelings of isolation and estrangement from family and other social support systems.

In stark contrast to the magnitude of CFS is the rather minimal federal effort dedicated to advancing understanding and promoting research into diagnostics, treatments and prevention. Based on NIH's public report of disease specific spending, funding for CFS research will be \$4 million this year and is expected to fall to \$3 million for FY10. CFS does not appear in any of the special announcements for funding opportunities under the American Recovery and Reinvestment Act (ARRA), although the CFIDS Association of America encouraged its funded investigators to apply under more general NIH Funding Opportunity Announcements under ARRA. NIH has targeted \$60 million in ARRA funds to stimulate research on autism spectrum disorders. In its March 24, 2009 press release, NIH states that, "Targeting Recovery Act funds toward objectives identified in the IACC strategic plan will help move the science forward sooner than anticipated in addressing some of the most significant challenges to understanding and treating ASD." The same could be said of an infusion of funding for CFS research.

The Association requests that NIH strengthen the network of investigators funded under the FY07 CFS neuroimmune research initiative by stimulating new research initiatives, building multicenter

collaborations and developing a data sharing and networking platform. It 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. Finally, the Association urges **NIH** to prioritize CFS research using funds from the Recovery Act and to ensure that study sections responsible for reviewing grants on CFS include experts who are qualified in the appropriate disciplines.

We await the draft of the five-year plan for the U.S. Centers for Disease Control & Prevention's CFS research program. The Association remains concerned about the lack of measurable progress demonstrated by the program located in the Chronic Viral Diseases Branch and is not convinced that sole source contracts with Abt Associates and Emory University have produced meaningful outcomes commensurate with the millions of dollars expended, in spite of CDC's assurances. The issue of the empiric classification of CFS patients used only by CDC remains a monumental stumbling block to collaboration and comparability, and the five-year plan should address this issue directly. In addition, the Association recommends that the following objectives be addressed in the plan:

OBJECTIVES	CDC ASSETS TO BE LEVERAGED	MEASURABLE OUTCOMES BY WHICH PROGRESS WILL BE EVALUATED
Resource maximization	Existing data sets from CDC-funded studies from 1992-present	Publicly available, continuously updated, searchable online subject-oriented relational database of all de-identified data from CFS research studies that have completed enrollment
Collaboration	Funds allocated to the CDC's CFS research program expand the overall research effort, rather than keep them concentrated in an insular group	Competitive grants, cooperative agreements & contracts with external research institutions totaling at least 50% of the budget allocation for studies that will reduce disease morbidity through early detection, objective diagnosis and improved management
Translation	Knowledge base accrued over last 25 years, including expertise represented by the multi-disciplinary CFS research group and its past/present collaborators and contractors	Rapid and broad dissemination of educational/informational tools (including articles in the peer-reviewed literature) for primary care providers, researchers and the public (including patients and caregivers)
Transparency	Priority-setting and accountability for CFS research and education programs that are supported by CDC	Semi-annual reporting on the specific uses of funds and progress toward measurable outcomes identified in the five-year plan; disclosure of problems and pitfalls of studies as they are identified
Partnership	Implementation of research and education tactics by knowledgeable, capable organizations with diverse expertise	CDC's active and direct engagement of a variety of stakeholders across public and private sectors in the research and education programs it supports

In the attached letter to acting director Dr. Richard Besser, the Association recommended that consideration be given to housing CFS activities in the National Center for Chronic Disease Prevention and Promotion. Dr. Besser has responded and indicated that this recommendation will be forwarded to the newly appointed CDC director, Dr. Thomas Frieden, as one of the options for agency-wide reorganizations being contemplated.

The other agencies represented on this committee have important roles in developing a more robust response to the public burden imposed by CFS, but the inadequate size and scope of biomedical research supported by federal health agencies remains the Association's top concern. The Association urges the CFSAC to forward these recommendations with its strong endorsement to Secretary of Health Sebelius and to actively pursue a deeper and more effective engagement with top officials in the department to ensure their swift adoption and enactment.

The Association commends Dr. Wanda Jones, her team and the NIH for making this meeting accessible by videocast and likewise appreciates the CDC's engagement of stakeholders by audioconference at its April 27 public meeting. We encourage all efforts to expand access to these types of proceedings and to enable participation by those whose lives have been most deeply affected by CFS. Thank you for the opportunity to submit these recommendations.

K. Kimberly McCleary  
President & CEO  
The CFIDS Association of America  
May 22, 2009

# The CFIDS Association of America

*Working to conquer chronic fatigue and immune dysfunction syndrome*

## MEMORANDUM

TO: E. Besser, Acting Director  
U.S. Centers for Disease Control & Prevention

FROM: K. Kimberly McCleary, President & CEO  
The CFIDS Association of America

DATE: March 11, 2009

RE: Chronic Fatigue Syndrome

Dr. Richard

As we approach the 25<sup>th</sup> anniversary of the CDC's study of chronic fatigue syndrome (CFS, also known as chronic fatigue and immune dysfunction syndrome or CFIDS) and with a new administration taking shape, it is timely to make some urgent recommendations to the new CDC leadership that recognize both the history and the future of CFS research at the agency. We believe that there are many promising advances possible with an invigorated approach to CFS that capitalizes the approach the agency has taken over the past quarter century, as well as current knowledge. On behalf of the estimated 4 million CFS patients living in the United States', the CFIDS Association of America submits the following memorandum for your thoughtful review and strong consideration.

### **Historical Context**

CDC first became involved in the study of CFS in response to a reported outbreak of illness made in 1985 by two internists practicing in Incline Village, Nevada. The first case definition, published by CDC authors in 1988,<sup>1</sup> coined the term "chronic fatigue syndrome" and established a framework for studying the condition. Although CDC could not pinpoint a cause or verify a cluster based on an outbreak investigation of Incline Village patients," the similarity between patients' reported symptoms and chronic Epstein-Barr virus (EBV) infection led to CFS being housed within the infectious disease programs at both CDC and the National Institutes of Health (NIH). Shortly thereafter, studies showed that it was unlikely that EBV was the causative agent for CFS,<sup>4</sup> and a search for novel infectious agents began. In spite of nearly 25 years of modestly funded research by the federal government and other organizations including the CFIDS Association of America, no single etiologic agent has identified, although recent studies have demonstrated that several viral and bacterial agents can trigger CFS.<sup>5</sup> Abnormalities in the immune, endocrine, autonomic nervous and central nervous systems have been documented by research groups at CDC and academic institutions around the world in approximately 5,000 peer-reviewed articles published in the medical literature. Still, there remains no objective diagnostic test and no effective therapy for CFS. CDC's studies indicate the level of functional impairment associated with CFS is the same as for COPD, late-stage AIDS and renal failure." The clinical course of CFS often follows a remitting and relapsing pattern; in one longitudinal study CDC found that CFS subjects were ill for a median of 6.3 years.<sup>1</sup> CDC estimates that CFS is responsible for an annual cost of \$9 billion in lost productivity alone.<sup>f</sup>

CDC published the first case definition in 1988 and in 1994 convened an international consensus panel that resulted in a revised definition." The 1994 definition remains the "gold standard" for CFS research despite publication of "empiric" criteria<sup>10</sup> by CDC authors in 2005. The empiric

criteria have not been adopted by established CFS researchers, including those with NIH support. CDC is the only group to have published research on CFS using the empiric criteria, limiting the comparability of studies supported by CDC.

Funding for CFS research at CDC increased following a 1998-99 investigation by the Inspector General that confirmed misuse of \$12.9 million in funds by CDC.<sup>11</sup> In response to Congressional and advocates' demands, the agency agreed in 1999 to restore funds to the CFS program over a five-year period. This "payback" period facilitated the expansion of the CFS research program to include laboratory and clinical studies, as well as a few selected collaborations which included a contract with the CFIDS Association of America to support increased awareness of diagnosis and management among primary care professionals. With the creation of the National Center for Health Marketing in 2005, CDC also let a contract to the CFIDS Association to develop and implement the first national public awareness campaign. This was a highly productive and collaborative period that was highlighted by CDC Director Dr. Julie Gerberding stating at a media briefing on April 20, 2006 that the CFS program's integrative approach was a model for other CDC programs like autism, where "an underlying genomic basis may set the foundation for other potential environmental events that trigger the expression of the disease.,<sup>12</sup> Later that year, Dr. Gerberding launched the public awareness campaign at the National Press Club on November 3, 2006, generating thousands of articles in the press and wire stories with validating leads such as, "CDC: CFS Real, Brutal.,<sup>13</sup>

This high point was quickly, and rather inexplicably, followed by a marked loss of scientific momentum in the CFS research program. Possible contributing factors include: the end of the payback funding; uncertainty about the program's placement within a new organizational structure; and the possibility of shifting the branch's HPV program from NCZVED to National Center for HIV / AIDS, Viral Hepatitis, STD, and TB Prevention (following FDA approval of the HPV vaccine). Contracts with Abt Associates and Emory University obligating millions of dollars failed to enroll patients according to timelines reported to Congress.<sup>14</sup> The group's publication rate fell sharply and prospective outside collaborators were turned away due to lack of funds. The program became increasingly insular and failed to communicate with academic investigators or other stakeholders about its studies and plans. In fact, the most recent program update available on the CDC's web site is dated August 8, 2005<sup>15</sup> and the last meeting hosted by CDC to explore research or clinical issues related to CFS was held September 18-21, 2005.<sup>16</sup>

Beginning in 2007, the Department of Health and Human Services (DHHS) CFS Advisory Committee issued several recommendations to the Secretary of Health aimed at restoring the program, but ultimately issued a statement of "no confidence" in program leadership at its November 28-29, 2007 meeting following a particularly tense exploration by appointed members of the ex-officio representative from the Chronic Viral Disease Branch.<sup>17</sup> Ex-officio representation to the DHHS CFS Advisory Committee was elevated from the branch to the center level in May 2008<sup>18</sup> in an effort to improve the agency's transparency and re-establish confidence among the committee members and the community. While this facilitated greater responsiveness to public concerns, close inspection of financial information provided by CDC to the DHHS CFS Advisory Committee, the CFIDS Association of America and Congress about the program's expenditures between 2005-2008 deepened concerns about the pace and progress of evidence-based research, based on the lack of a strategic plan, lack of appropriate oversight by Coordinating Center for Infectious Diseases (CCID) leadership, and lack of accountability for spending priorities by branch staff  
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Congress has recognized this problem and has urged the CDC to take appropriate corrective measures. In its FY2009 Report on the Departments of Labor, Health and Human Services, and

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Education, and Related Agencies Appropriation Bill, the Senate Committee on Appropriations stated, "The Committee has included funding to continue the chronic fatigue syndrome activities at no less than last year ... the Committee strongly supports a robust CFS research program, but is concerned by the diminished number of research findings being published by the CDC on this subject."

#### **Convergence of External Expert Panels' Conclusions**

Over the agency's 25-year involvement in CFS research, four panels of outside experts have been convened to peer-review the program and provide recommendations regarding priorities and promising avenues of discovery. The following bodies have made written recommendations to the agency:

External Peer Review: August 28-29, 1996

External Peer Review: November 15-16, 1999

External Blue Ribbon Panel (EBRP): January 30-31, 2007

External Peer Review: November 5-7, 2008

In addition, the General Accountability Office made a report to Congress on the CFS programs at CDC and NIH in 2000?2 The CCID Board of Scientific Counselors also heard a presentation about the program on May 12, 2006 and was asked to lend its advice to CCID Director Mitchell Cohen about the optimal placement of the research program within the CDC.

Written reports were issued after each of the peer reviews, the EBRP meeting and the GAO study. Each of the reports issued reflects the current investigations and prevailing theories at the time of their meeting, but there are important recurrent themes found in all the reports made across this 14- year time period. These repeated themes provide important direction for CDC's current and future efforts to reduce morbidity associated with and to control and prevent CFS. Each of these panels concluded that CDC should place greater emphasis on:

1. Enhancing collaborations with NIH and extramural and intramural scientists;
  2. Sharing data accumulated by the program with other investigators;
  3. Establishing a biorepository for samples collected from community-based studies;
  4. Conducting natural history studies to better understand clinical course and prognosis of CFS;
- and,
5. Expanding communication with the public and to work aggressively against insularity of program.

These conclusions echo those reached by the CFS Advisory Committee and the CFIDS Association of America over the past 18 months. Both of these bodies, as well as the 2008 External Peer Review Panel, have urged CDC to develop a multiyear strategic plan to guide the program. It was recently confirmed by senior U.S. Senate appropriations staff that NCZEVD is developing such a plan; however, it has not yet engaged stakeholders in the planning process as has been emphasized in past expert panels' recommendations. This insularity is further demonstrated by the fact that CDC's CFS research program does not intend to be represented by any of its senior investigators or team leaders at the 9<sup>th</sup> biennial CFS research conference taking place March 12-15, 2009 in Reno, Nevada.

#### **Funded Studies Significantly Delayed and Study Outcomes Uncertain**

Reports to Congress and the DHHS CFS Advisory Committee made by CDC about its CFS research program have consistently emphasized the following activities as programmatic and spending

priorities since 2005; however, as of this date, outcomes for these activities have fallen far short of commitments made to Congress and other stakeholders:

- o Surveillance of CFS and Unwellness in Georgia: So far, this study for which a total of \$3,167,516 has been obligated for payment to contractor Abt Associates has produced just six publications, including the paper estimating CFS prevalence at 4 million" using the controversial empiric case criteria.<sup>24,25</sup> Although the study commenced in May 2004, as of the end of FY08 only \$1,542,449 had been spent, signaling a lack of strategic direction, accountability and performance by CDC program management and the contractor.
- o CFS Patient Registry in Georgia: Planning for this activity is reported to have begun in 2004, yet its "kick-off" event did not occur until February 23, 2009. The registry's website.r" indicates that health care providers are encouraged to refer patients for enrollment for a one-year period beginning September 2008. Thus, the kick-off event took place five months into the one-year enrollment period and not until after \$2.2 million had been obligated to Abt Associates for developing the registry.
- o Two-Day Clinical Study at Emory University's General Clinical Research Center: The CDC's single active collaboration with an outside academic institution is a two-day in-hospital study of pathophysiologic mechanisms of CFS that will enroll 30 CFS subjects and 60 controls. This study, announced in 2005, did not enroll its first subject until April 2008. Contracts with Abt Associates and Emory University, including intergovernmental personnel agreements, have already consumed \$4.5 million for FY2005-08 and CDC has stated its plans to dedicate additional funds to the study over the coming years.

Finally, the topic of lack of CDC's engagement in identifying appropriate interventions for CFS as part of its stated control and prevention objectives has been raised in multiple meetings, including the 2007 External Blue Ribbon Panel meeting and more recent DHHS CFS Advisory Committee meetings. In response to questions about programs plans to more adequately address interventions, branch chief Dr. William Reeves stated that CDC would convene a meeting in spring 2008 of established CFS researchers and clinicians to help establish guidelines for patient care.<sup>27</sup> To date, no such meeting has been announced or held. At the May 5, 2008 meeting of the DHHS CFS Advisory Committee, Dr. Reeves indicated that the Macon, Georgia, clinic being used for the patient registry might be used to conduct intervention studies/" but no additional details about this are available on the CDC's website or the independent website created to house information about the patient registry.

### **Program Objectives Better Suited to Programs Maintained for Chronic Conditions**

Based on an exhaustive review of all of the expert documents, all of CDC's publicly available CFS program plans and materials, and reports on past programmatic and financial performance made by CDC, it appears that the objectives of the agency's effort to "devise control and prevention strategies for CFS" is more appropriately suited to the mission and expertise housed in the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). According to the CDC's website, the National Center for Chronic Disease Prevention and Health Promotion "is at the forefront of the nation's efforts to prevent and control chronic diseases. The center conducts studies to better understand the causes of these diseases, supports programs to promote healthy behaviors, and monitors the health of the nation through surveys. Critical to the success of these efforts are partnerships with state health and education agencies, voluntary associations, private organizations, and other federal agencies. Together, the center and its partners are working to create a healthier nation.,,29 The

description of NCCDPHP's activities as stated in the Congressional Justification for FY2009 incorporates many of the activities now being conducted in the CFS research program, although NCCDPHP reports more successful outcomes than has the CFS research program in maintaining activities such as patient registries, identifying clinical interventions and maintaining multi-year surveys of ill populations. There are numerous applicable models described in the Congressional Justification that would be immediately portable to CFS, such as established programs for lupus, arthritis and other chronic diseases. The CFS research program's current allocation of approximately \$5 million would be sufficient to initially support these types of programs.

Contrast the NCCDPHP's mission with the stated purpose of the National Center for Zoonotic, Vectorborne and Enteric Diseases (NCZVED) where the CFS research program now resides: "NCZVED provides leadership, expertise, and service in laboratory and epidemiological science, bioterrorism preparedness, applied research, disease surveillance, and outbreak response for infectious diseases. This new Center brings together some of the oldest components of the agency - those dealing with viral, bacterial, parasitic, and other communicable diseases. ZVED combines these functions in a multidisciplinary strategy to understand, prevent, control and - where possible - eliminate infectious diseases within a larger ecologic context.,<sup>30</sup> Following the May 12, 2006 presentation about CFS to the CCID Board of Scientific Counselors there was considerable internal discussion about the appropriateness of housing CFS in a center dedicated to infectious diseases when, in fact, CDC's own studies had failed to classify it as such. Nearly three years later, progress toward understanding CFS as a chronic condition with multiple triggering and perpetuating factors has stalled and the lack of program staffs experience in dealing with chronic conditions, particularly in establishing and maintaining the type and variety of partnerships and collaborations recognized as being critical to the study of chronic conditions, is undoubtedly one of the essential elements currently missing from the agency's approach to CFS.

#### Specific Recommendations:

##### 1. Freeze New Contracts and Additional Contract Obligations

Until such time as the new strategic plan for CFS activities at CDC is complete, the CFIDS Association recommends that a spending freeze be placed on all new contracts or further obligations to existing contracts. Based on the spending patterns detailed in reports provided by CDC to the Association, the CFS Advisory Committee and Congress, sufficient funding to continue ongoing research has been obligated. Upon the completion of the five-year plan, all current and pending CFS-related contracts should be re-evaluated to ensure that they are consistent with the goals and objectives of the plan.

##### 2. Relocate CFS Activities to the Coordinating Center for Health Promotion

Based on the respective missions of CDC's coordinating centers and the stalled progress of CFS activities in the current organizational home within CCID, the CFIDS Association of America recommends that new leadership be identified in the NCCDPHP to focus its more relevant expertise and demonstrated track record of success, consistent with the aims set forward for NCCDPHP in the FY 2009 Congressional Justification: "To prevent the onset of chronic diseases, identify early the presence of chronic disease and associated complications and reduce progression of the basic chronic condition and/or associated complications; improve the care and management of those impacted by chronic diseases; and promote healthy behavior choices through education, community and societal policies to reduce the burden of chronic diseases."

Once relocated, the first action step should be to seek active participation of the CFIDS Association of America and other stakeholders to develop a five-year strategic plan consistent with NCCDPHP's broad and deep experience addressing chronic conditions that occur across the lifespan and are more similar to CFS than those that are studied in NCZEVD. We believe that engaging new program leadership within NCCDPHP and establishing this multiyear strategic plan, identifying staff with the experience to facilitate collaborations inside and outside the agency and manage a robust set of contracts, cooperative agreements and grants is absolutely critical to re-establishing forward momentum by CDC on the control and prevention of CFS.

### **3. Share Data Already Accumulated**

As has been requested by the Association and the DHHS CFS Advisory Committee on multiple occasions and was outlined most recently in a February 10, 2009 letter to NCZEVD director Dr. Stephen Monroe," the Association urges CDC to promptly make available all the epidemiologic, clinical and laboratory data from studies conducted by the CFS research program since 1984, consistent with existing CDC policy and President Obama's January 21, 2009 memorandum instructing openness and transparency. "All agencies should use modern technology to inform citizens about what is known and done by their Government. Disclosure should be timely...,"<sup>32</sup> Dr. Monroe's February 17, 2009 reply<sup>33</sup> does not contain any timeline for making data publicly available, other than a reference to the completion of a new Atlanta facility for the National Center for Health Statistics. The release of the accumulated CFS data will facilitate continuing research related to CFS, ensure that work is not duplicated and ensure that new funds are not spent unnecessarily. In addition, the release of this data will increase the efficiency and evidence-based nature of CFS research by: 1) using standard instruments to record key symptoms, measure functional impairment, and identify comorbid or exclusionary conditions; 2) using standard methods of sample collection, handling, storage and standardized assay methodologies in order to minimize sources of variation in laboratory parameters; and, 3) validating constructs and biomarkers.

### **4. Consistently Report on Spending**

In order to track and review CFS research funding at the CDC and to maintain a high degree of transparency and accountability, the CFIDS Association recommends that the CDC continue to include in its annual budget justification an itemized expenditure of funds for each 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 health care 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.

In conclusion, we deeply appreciate the opportunity to submit this set of recommendations, as well as a thoroughly documented summary of past and present weaknesses and opportunities for CFS activities at CDC, for your consideration. We are committed to fulfilling the promise of the CDC's contributions to understanding, controlling and preventing CFS. We would welcome the opportunity to meet with you and your staff to discuss this memorandum and our recommendations in greater detail and will accommodate your schedule in order to do so.

The CFIDS Association of America is the largest and most active organization dedicated to making CFS a diagnosable, treatable, curable and preventable condition by stimulating research aimed at the early detection, objective diagnosis and effective treatment of CFS through expanded public, private and commercial investment. Since its founding in 1987, the Association has funded more than \$26 million in research, policy and education programs and has become the independent sector's most widely recognized authority on CFS.

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