

**TESTIMONY OF
K. KIMBERLY KENNEY
President and Chief Executive Officer of
THE CFIDS ASSOCIATION OF AMERICA**

**before
THE HOUSE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND
RELATED AGENCIES
APPROPRIATIONS SUBCOMMITTEE**

Thursday, May 2, 2002

Mr. Chairman, good afternoon and thank you for the opportunity to appear before the Committee today. My name is K. Kimberly Kenney and I am President and Chief Executive Officer of The CFIDS Association of America. The CFIDS Association is the leading organization working to conquer chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS).

Since 1987, the Association has invested over \$12 million in education, public policy and research programs in its efforts to bring an end to the suffering caused by the illness. There is a critical need for information about CFIDS — the Association receives inquiries from people living in every state and many countries around the world. In 2001, nearly 350,000 Web site visits over 6,000 personal requests for information were recorded.

CFIDS is a serious and complex illness that affects many body systems. There is no known cause and no diagnostic test. CFIDS is characterized by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), neurological problems and numerous other symptoms. It can be severely debilitating and can last for many years. CFIDS is often misdiagnosed because symptoms overlap with other disorders including mononucleosis, multiple sclerosis, fibromyalgia, Lyme disease, post-polio syndrome and autoimmune diseases such as lupus.

CFIDS strikes people during the prime of their most productive years. Studies have shown that nearly 1 million American adults and children have CFIDS, but only 10% of them have been diagnosed. It is three times more common in women than it is in men, and it disproportionately affects blacks and Hispanics and persons of lower socioeconomic status. Although few long-term studies of the illness have been done, CDC estimates the recovery rate to be less than 12%.

On behalf of those affected by CFIDS, I will make requests of this Committee for its continued support of activities that are critical to improving the understanding of CFIDS. The CFIDS Association's goal is to advance CFIDS biomedical research and, ultimately, to eradicate the illness. CFIDS patients are dependent upon scientific process, and in particular research funded by the Centers for Disease Control and Prevention, the National Institutes of Health (NIH) and other federal agencies, to discover the cause(s), diagnostic tests, effective treatments and ultimately a cure for this debilitating illness.

Secretary for Health

In 1996, Health and Human Services Secretary Donna Shalala chartered the Chronic Fatigue Syndrome Coordinating Committee (CFSCC), providing a forum for advocates, researchers, clinicians and federal health officials to promote better understanding and resolve challenging policy issues. The CFSCC enhanced communication, improved collaboration, prevented duplication and strengthened CFIDS programs supported both by the federal government and private foundations.

In its 1999 report on Public Health Service CFIDS programs, the General Accounting Office noted that the CFSCC's structure was unlike other DHHS advisory committees, in that it had a federal chairperson and agency representatives had full voting privileges. In January 2001, the Committee co-chair announced that DHHS had initiated efforts to convert the CFSCC to full DHHS advisory committee status and that nominations would soon be sought for new members and a non-federal co-chair. More than 15 months have passed since this announcement and no action has been taken to form this new committee. The lengthy delay has jeopardized momentum building in federal efforts to appropriately address this disease. Trust that was developing between the patient community and federal health agencies has eroded during this period of inaction and many are skeptical that the new committee will ever meet.

The new advisory committee must be formed without further delay and its new structure must not diminish the full partnership of involved agencies or the collaborative relationships among federal agencies, scientists, and CFIDS advocates that have developed over recent years through the CFS Coordinating Committee.

Request: The Association asks that the Committee convey its displeasure that the Department's Chronic Fatigue Syndrome Advisory Committee, announced in January 2001, has not been formed, jeopardizing momentum and important partnerships between the member agencies and the CFIDS community. We ask that the Committee direct the Department to immediately approve the CFS Advisory Committee Charter, publish a call for nominations, install members and hold one meeting prior to the end of calendar year 2002.

Centers for Disease Control and Prevention

Following a report from the Inspector General that documented \$12.9 million in CFIDS funds had been diverted to other programs, CDC began restoring this money to the CFIDS research program in 1999. The "payback" was mandated by Congress to occur over a four-year period (1999-2003), mirroring the four-year period over which the misuse of funds occurred (1995-98).

The CFIDS Association of America considers these funds to be very precious, and has worked closely with CDC's top leadership and the CFS program to ensure that these funds are used to strengthen the agency's research program. Largely as a result of this collaboration, the CDC has built a sturdy foundation for current and future CFIDS research; however, only half of the \$12.9 million has been expended with only 17 months remaining in the payback period. So that the remaining funds continue to be effectively used, the Association supports a one-year extension of the payback period, and strongly encourages provision of sufficient baseline funding to accelerate the agency's CFIDS research programs.

Request: The CFIDS Association asks the Committee to encourage CDC in its support of new and important areas of CFIDS research and medical education. We ask the Committee to

instruct CDC to extend the payback period by one year, through FY'04, and to provide sufficient baseline funding to accelerate its CFIDS research plan to identify the causes, risk factors, diagnostic markers, natural history and economic impact of CFIDS; to create a CFIDS patient registry; to expand important collaborations with academic researchers; and to educate health care providers about the detection, diagnosis and management of CFIDS.

National Institutes of Health

Despite the generous budgetary increases Congress has provided NIH toward doubling its budget, the agency's CFIDS research spending has stagnated. CFIDS funding nearly tripled from 1990-95, but fell by 16% over the following five years. In fact, FY2000 CFIDS spending was only 84% of 1995 spending. Congress' intent, that these large overall increases would benefit all research areas, has failed CFIDS research. According to newly released surveys, numerous health organizations report that NIH support has not benefited all areas of research evenly. As new money continues to pour into NIH, a new strategy is required to more effectively distribute these funds beyond the most popular areas of research.

In December 2001 NIH released the first CFIDS program announcement in five years. The Association hopes that this initiative will reverse seven years of declining CFIDS funding at NIH. However, problems with the grant review process persist and researchers report to our organization that there is little encouragement from NIH program staff to cultivate promising research. Additionally, NIAID has informally announced that the funding of Cooperative Research Centers, a provision of the NIH Reauthorization bill now in force, will be discontinued. Research centers offer investigators the opportunity to develop collaborative research efforts spanning multiple disciplines and areas of expertise. CFS center grants have formed the core of NIH's research effort and have generated important findings. An NIH state of the science conference held in late 2000 affirmed the need for CFS research to employ a multi-disciplinary approach. NIAID's decision to discontinue funding for these multidisciplinary centers is contrary to recommendations made by its own advisors.

CFIDS patients rely on medical research not only for information about the possible causes of their illness and treatments for it, but also for hope of a healthier future. Researchers are drawn to new areas of scientific inquiry by two factors: scientific curiosity and available funding. Efforts begun in 2001 to build interest in CFIDS among the many NIH institute program staff must continue and outreach to researchers working in related fields must be expanded. There must be an unequivocal statement from NIH that CFIDS research is a funding priority if we are to reverse the dismal trend of funding and interest.

Request: The Association asks Congress to direct NIH to allocate an additional \$10 million in grants to focus on promising areas of CFIDS research, such as efforts to understand the cause and progression of CFIDS, identify diagnostic markers and focus on pediatric CFIDS, by funding both multidisciplinary CFIDS research centers and investigator-initiated studies. The Association requests that the Committee underscore the need for active outreach to the research community to attract new investigators to the field and to continue NIH campus activities that will foster interest among program officers and intramural researchers.

Department of Education

CFIDS affects people of all ages, including children, adolescents and teenagers. Having CFIDS

can be particularly difficult for young people because it affects them at a time of crucial intellectual, social and physical development. Many students with CFIDS have great difficulty securing appropriate educational accommodations by their local school districts, despite federal educational laws such as the Individuals with Disabilities Education Act and the Rehabilitation Act of 1973 that mandate the free and appropriate education of students with disabilities and illnesses. The Department of Education's Office of Special Education Programs (OSEP) can aid students with CFIDS to access accommodations from their local educational authorities by informing educators about CFIDS and the special educational needs often required by students with CFIDS.

The CFIDS Association of America is very pleased that the National Institute on Disability and Rehabilitation Research has included CFIDS in its list of unmet areas of research and is funding a CFIDS research study. We encourage NIDRR to continue its support of CFIDS research.

Request: The CFIDS Association asks the Committee to share its concern about reports that students with CFIDS are not receiving appropriate educational accommodations and to instruct the Office of Special Education Programs to inform educators about CFIDS and the special educational needs often required by students with CFIDS.

We ask the Committee to encourage NIDRR to continue its support of CFIDS as an unmet area of research and to pursue CFIDS-related research proposals through its investigator-initiated and other grants programs.

Health Resources and Services Administration

Despite nearly two decades of research on CFIDS, scientific advances have not translated into improved clinical care for persons with CFIDS. In fact, CFIDS patients frequently cite their most difficult problem is locating effective, compassionate medical care. They often go from provider to provider in search of a practitioner who can provide appropriate symptomatic care, information and referrals.

HRSA has supported collaborative efforts with The CFIDS Association of America to develop and implement an educational curriculum for primary care providers about CFIDS. To date over 1,800 primary care providers have learned about the detection, diagnosis and management of CFIDS. The education of health care providers is just one element of the effort required to improve medical care of CFIDS patients.

Over the years, HRSA has supported demonstration grants to develop new, more effective ways of health care delivery for emerging illnesses, although not yet for CFIDS. A grant of this nature would enable the development of centers to explore the optimum care of CFIDS patients, incorporating various medical, rehabilitation and adjunctive care services. The cost savings yielded from a more strategic approach to case management is ample justification for this investment.

Request: The CFIDS Association asks the Committee to direct HRSA to provide demonstration grants to develop model CFIDS clinical centers with the goal of delivering effective, multidisciplinary clinical care to persons with CFIDS.

Social Security Administration

Social Security Ruling 99-2p, Evaluating Cases Involving Chronic Fatigue Syndrome, appears to have greatly improved the ability of persons disabled by CFIDS to access Social Security disability benefits. In spite of this ruling that is binding at all stages of the review process, there remain many SSA/DDS employees unfamiliar with or misinformed about CFIDS and the functional limitations it imposes. This lack of information leads to unnecessary delays in awarding benefits and increased costs to SSA, as favorable decisions are often made at later stages of the adjudication process. To quantify the impact of the Ruling, SSA implemented a tracking program in 2000, although the agency has not yet reported any data to the CFIDS community on the program.

Request: We ask the Committee to encourage SSA to continue CFIDS-related educational efforts, to examine current obstacles to benefits for persons with CFIDS, to assess and report the impact of the ruling on CFIDS patients' access to benefits, and to keep medical information updated throughout all levels of the application and review process

