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Chronic fatigue and immune dysfunction syndrome (CFIDS, also known as chronic fatigue syndrome, CFS, myalgic encephalomyelitis, ME and by many other names) is a complex and debilitating chronic illness that affects the brain and multiple body systems. On this portion of our Web site you can find detailed information about CFIDS, its symptoms, diagnosis, treatment, important research findings, and how it affects the lives of those who live with it everyday.

Whether you are a person with CFIDS, a medical professional, a caregiver, or just curious, we hope that the information you find here will improve your understanding of this devastating illness that affects more Americans than multiple sclerosis (MS), AIDS or lung cancer.

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Symptoms

Although its name trivializes the illness as little more than mere tiredness, chronic fatigue and immune dysfunction syndrome (CFIDS) brings with it a constellation of debilitating symptoms.

CFIDS is characterized by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina) and problems with concentration and short-term memory. It is also accompanied by flu-like symptoms such as pain in the joints and muscles, unrefreshing sleep, tender lymph nodes, sore throat, and headache.

Persons with CFIDS (PWCs) have symptoms that vary from person to person and fluctuate in severity. Specific symptoms may come and go, complicating treatment and the PWC's ability to cope with the illness. Most symptoms are invisible, which makes it difficult for others to understand the vast array of debilitating symptoms with which PWCs contend.

Other Common Symptoms

The primary symptoms described in the CDC's case definition are listed above. Also common to CFIDS are cognitive problems such as difficulties with concentration and short-term memory, word-finding difficulties, inability to comprehend/retain what is read, inability to calculate numbers, and impairment of speech and/or reasoning. PWCs also have visual disturbances (blurring, sensitivity to light, eye pain, need for frequent prescription changes); psychological problems (depression, irritability, anxiety, panic attacks, personality changes, mood swings); chills and night sweats; shortness of breath; dizziness and balance problems; sensitivity to heat and/or cold; alcohol intolerance; irregular heartbeat; irritable bowel (abdominal pain, diarrhea, constipation, intestinal gas); low-grade fever or low body temperature; numbness, tingling and/or burning sensations in the face or extremities; dryness of the mouth and eyes (sicca syndrome); menstrual problems including PMS and endometriosis; chest pains; rashes; ringing in the ears (tinnitus); allergies and sensitivities to noise/sound, odors, chemicals and medications; weight changes without changes in diet; light-headedness; feeling in a fog; fainting; muscle twitching; and seizures.

For More Information

Although The CFIDS Association of America does not dispense medical advice on the diagnosis or treatment of chronic fatigue and immune dysfunction syndrome (CFIDS), chronic fatigue syndrome (CFS), or similar conditions, we do have an interactive questionnaire to familiarize site visitors with the symptom patterns and exclusions that can lead a health care provider to make a diagnosis of CFIDS.

To request a copy of "Understanding CFIDS" or another free Association brochure, [please click here](#).

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Diagnosis

Diagnosis of chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS), is a time-consuming and difficult process which is generally arrived at by excluding other illnesses with similar symptoms and comparing a patient's symptoms with the 1994 International case definition.

As yet, there is no indicator or diagnostic test that can clearly identify the disorder. Overlapping symptoms can occur with several diseases, such as fibromyalgia, Gulf War Illnesses, and multiple chemical sensitivities. Lupus, hypothyroidism, and Lyme disease also have similar symptoms and will need to be ruled out when making a diagnosis.

Related Information

- [Diagnostic Testing](#)
- [Viruses](#)

What You Can Expect

Your physician will take a medical history, asking questions about your past health (you will probably be asked to complete a written form - often done before your appointment time). It is likely that you will be asked about your past and current mental health as well. You can expect to receive a basic physical exam. Several types of routine blood tests and those that exclude alternative diagnoses are almost certain to be ordered. Other tests that are designed to identify central nervous system problems or viral syndromes may be ordered as well, depending on your symptoms. It's important to answer questions honestly and completely - and don't hesitate to ask your own questions. If you have thought of questions before your appointment, it's a good idea to write these down and bring them with you. Also, bring a list of medications and supplements that you're taking - be sure to include dosages. In addition, bring paper and pen with you to write down instructions. If possible, ask your provider if you may tape record your consultation so that you can review it and make decisions in a fully informed manner.

Diagnostic Criteria / Case Definition

The Centers for Disease Control and Prevention updated the case definition for CFIDS in 1994. Although the criteria were designed to be used for research purposes, physicians utilize them as diagnostic guidelines for CFIDS. The case definition criteria calls for four of eight symptoms to be present along with fatigue that interferes with physical, mental, social and educational activities. Both the fatigue and symptoms must have occurred for [at least] a six month period. Persons with CFIDS may experience many more than the eight symptoms named in the case definition, so knowledgeable physicians will take this fact into consideration when making a diagnosis (after other possible reasons for symptoms have been ruled out).

Waiting for the Diagnosis

After testing has been completed and the physician has ruled out alternative diagnoses, he/she will inform you of the probable diagnosis. If you have research articles and other CFIDS factual information, you may wish to share this with your doctor while in the diagnostic process. With CFIDS, it's not uncommon for patients to be better informed than many physicians, so feel free to courteously share your knowledge. The diagnostic process may be lengthy - some persons wait many months (or years) to be diagnosed. It may take an enormous amount of patience. In the meantime, ask your doctor to treat your symptoms to obtain some relief and improve function.

We're Here for You

If you are typical of the person with CFIDS, obtaining a diagnosis has been a frustrating experience. You are not alone in your frustration. Support and understanding are offered at The CFIDS Association Web site. You're invited to continue your search through the Association's Web site to discover more about treatment, research, support, resources, as well as the [benefits of membership](#) in the Association.

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Treatment

Treating chronic fatigue and immune dysfunction syndrome (CFIDS) presents a significant challenge to persons with CFIDS and their physicians. As yet, there is no known cause, cure, or universal treatment for CFIDS. Until a treatment is developed which will improve all the symptoms of CFIDS, or correct the underlying cause, therapy is based upon the individual's presenting symptoms.

[Medical Treatments](#)

Medications that provide symptom relief are frequently the first line of treatment chosen by primary care providers for the person with CFIDS. These include medications for pain; sleep disturbances; digestive problems such as nausea; depression and anxiety; and flu-like symptoms. Medications may be supplemented by supportive therapies.

[Supportive Treatments](#)

Therapies that help persons to relax and improve coping skills fall into this category and may include counseling for emotional and mental health, cognitive behavioral therapy, sleep management therapy, and massage.

[Alternative Treatment](#)

Many persons find complementary therapies such as acupuncture, tai chi, and alternative food and herbal supplements to be helpful. Please note that adding food and herbal supplements to your therapy regimen needs to be done with care and with your physician's and pharmacist's knowledge to prevent undesirable side effects.

[Lifestyle Alterations](#)

Altered digestion, food intolerances, decreased energy, fatigue, cognitive problems, and sleeplessness create the need for revisions in daily living routines. These can include changes in diet; exercise modifications; alterations in activities of daily living according to one's energy level; and sleep/rest management. All may require the assistance of professional clinicians, such as a dietitian, physical and/or occupational therapist, mental health professional, and sleep therapist.

[Other Treatment Options](#)

For persons who have been diagnosed with an autonomic nervous system abnormality, such as neurally mediated hypotension (NMH) or postural orthostatic tachycardia syndrome (POTS), fluid and salt loading may be a treatment of choice. Surgery for Chiari malformation, a defect in the area where the lower brain/spinal cord meet, is a treatment option for persons who have been found to have this malformation.

[Summary](#)

Treatment may incorporate any, or all, of the above categories as persons with CFIDS seek to improve their condition. The person with CFIDS can experience much frustration when attempting to secure treatment. Keeping an open mind and speaking candidly with a health care provider is important to any treatment plan.

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Research

Chronic fatigue syndrome (CFS) was first defined in 1988 by the U.S. Centers for Disease Control (CDC)¹ as an illness of at least six months duration which begins suddenly with flu-like symptoms, causes a minimum of 50% reduction in activity, and cannot be explained by alternate medical or psychiatric diagnoses.

Since that time, research has tried to solve the mysteries of CFS -- such as what causes it, how many people have it, how can we treat it. There is a long way to go -- there is still no laboratory marker or universal treatment for CFS -- but progress is being made.

[Diagnosis](#)

In 1994, the CDC revised its CFS case definition.² Because there is no simple laboratory test that can identify CFS, a physician must exclude other possible causes of the symptoms before diagnosing a person with CFS.

To meet the definition for CFS, a person must have clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest and results in substantial reduction in previous levels of occupational, educational, social or personal activities. In addition, the person must have at least four of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without swelling or redness; headaches of a new type, pattern, or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours.²

[Epidemiology](#)

Of every 100,000 Americans, 422 have CFS, and only 10% who meet the definition have been diagnosed.³ It is most common in women (522 cases per 100,000) and minorities, especially Latinos (726 cases per 100,000), but people in all race, age, and socioeconomic groups get CFS.

Full improvement is uncommon, with only 4% of patients recovering and 39% showing improvement after four years.⁴ Persons with CFS (PWCs) who have been ill for many years have special needs; please see our resources for long-term PWCs.

[Viral Triggers](#)

Because most cases of CFS begin with a flu- or mono-like illness, many viruses, bacteria, and toxins have been studied as possible causes of CFS. Most, including Epstein-Barr virus, have been excluded because of their relative commonness in the general population and the inability to link any pathogen to all cases of CFS.

Three pathogens now being studied closely in CFS are the human herpesvirus-6 (HHV-6),⁵⁻⁹ Chlamydia pneumoniae,¹⁰ and various forms of mycoplasmas.⁴¹ Of particular interest, the first two have also been linked to multiple sclerosis and the third to Gulf War illness, illnesses that share many clinical features with CFS.

Even so, there is still much debate in scientific circles over whether either of these agents -- or any pathogenic agent -- will emerge as the only cause of CFS. Current thinking is that there may ultimately be found several triggers of the CFS pathophysiology in genetically, environmentally, or otherwise susceptible individuals.¹¹

[Immune Dysregulation](#)

Immune system abnormalities have been found in PWCs, although none has emerged as a diagnostic marker. The most consistent findings are diminished natural killer cell function,¹² generalized immune system upregulation,¹³ and dysfunction in the 2-5A synthetase RNase L antiviral pathway.¹⁴⁻¹⁸

RNase L fights infection by degrading viral RNA. Temple University researchers have found that PWCs have a novel low molecular weight (37kDa) form of this enzyme and low levels of normal RNase L (80kDa). Studies are underway to determine if the unique RNase L is present in other diseases and whether it might serve as a marker for CFS.

Another new finding of interest is the discovery of autoantibodies to lamin B-1, a component of the cellular structure, which has led to increased speculation that CFS may be an autoimmune disease.^{19,20}

In October 2001, The CFIDS Association of America will sponsor a research symposium on immune abnormalities in CFS to chart directions for future research in this area.

Dysautonomia

In 1995, Johns Hopkins researchers reported that up to 95% of PWCs have neurally mediated hypotension, a condition in which the blood pressure falls when it should rise.²¹ This has become a dynamic area of CFS research and scientists are actively debating the nature of this and other forms of orthostatic intolerance.²¹⁻²⁶ Recent studies have focused on three possible keys to understanding orthostatic intolerance in CFS: low blood volume,²⁴ abnormal sympathetic tone,²⁵ and neurological dysfunction. One research group has proposed that the orthostatic intolerance in the most severely ill PWCs may be caused by low circulating blood volume, while in less ill persons orthostatic intolerance may be related to neurological dysfunction.²⁶

In December 2000, The CFIDS Association of America sponsored a research symposium on dysautonomia in CFS to chart directions for future research in this area.

Brain Abnormalities

Abnormalities on brain scans have been reported by several research groups.²⁷⁻³¹ Bright signals in the white matter on MRI have been found in about half of PWCs. Abnormalities on SPECT scans are more striking, and appear to correlate with clinical status.²⁷⁻²⁸ PWCs show SPECT brain perfusion deficiencies most commonly in the lateral frontal and temporal cortexes and basal ganglia.²⁷⁻²⁸ Neuropsychological testing has been helpful in quantifying the disabling cognitive problems PWCs report.³²⁻³⁷ The most well-documented abnormalities appear to be in attention and information processing.

Research has shown that the memory and concentration deficits are independent of any depression experienced by PWCs^{32,33} and physical and/or mental exertion worsens these symptoms for several days afterward.³⁴

Endocrine Dysfunction

Researchers at the National Institutes of Health attempted to treat low circulating cortisol, which has been found in PWCs,^{38,39} with hydrocortisone. While two-thirds of treated patients saw symptomatic improvement over the course of the study, the researchers concluded that hydrocortisone was not an advisable treatment for CFS because of the high risk of adrenal suppression while on this therapy.³⁹

Scientists in the U.K. have found that PWCs with low cortisol have abnormally small adrenal glands.⁴⁰ In the PWCs in this study, the adrenal glands were half the size of normal, while in depression they are enlarged up to 70%.

In March 2001, The CFIDS Association of America sponsored a research symposium on neuroendocrine abnormalities in CFS to chart directions for future research in this area.

Related Information

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- [Research symposium](#)
- [Research grant information](#)
- [Health care provider resources](#)
- [Case definition](#)
- [Long-term patient resources](#)
- [CFS research studies](#)

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How many people have CFIDS?

A study conducted by researchers at DePaul University estimates CFS at approximately 422 per 100,000 persons in the U.S. This means as many as 800,000 people nationwide suffer from the illness. 90% of patients have not been diagnosed and are not receiving proper medical care for their illness (Jason LA, Richman JA, Rademaker AW, Jordan KM, Plioplys AV, Taylor RR, McCreedy W, Huang CF, Plioplys S: A Community-Based Study of Chronic Fatigue Syndrome Arch Int Med 1999; 159(18):2129-37.).

Who gets CFIDS?

CFIDS does not discriminate. It strikes people of all age, racial, ethnic, and socioeconomic groups.

Research has shown that CFIDS is about three times as common in women (522/100,000) as men, a rate similar to that of many autoimmune diseases, such as multiple sclerosis and lupus. To put this into perspective, CFIDS is over four times more common than HIV infection in women (125/100,000), and the rate of CFIDS in women is considerably higher than a woman's lifetime risk of getting lung cancer (63/100,000).

Although few studies of CFIDS in children and adolescents have been published, it is well-accepted that [young people](#) do get CFIDS.

To read more about the DePaul prevalence study and for an interview with its lead author, visit the Association's online [Chronicle archives](#). To obtain a complete copy of the DePaul prevalence study, visit the Association's [on-line store](#).

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Complete Text of Revised Case Definition

Fukuda et al, Annals of Internal Medicine, Vol. 121, December 15, 1994, pp. 953-959.

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[Appendix](#)

The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study

Keiji Fukuda, M.D., M.P.H., Stephen E. Straus, M.D., Ian Hickie, M.D., F.R.A.N.Z.C.P., Michael C. Sharpe, M.R.C.P., M.R.C. Psych., James G. Dobbins, Ph.D., Anthony L. Komaroff, M.D., F.A.C.P. and the International Chronic Fatigue Syndrome Study Group

From the Division of Viral and Rickettsial Diseases, National Center for Infectious Diseases, Centers for Disease Control and Prevention, Atlanta, Georgia; Laboratory of Clinical Investigation and Division of Microbiology and Infectious Diseases, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, Maryland; School of Psychiatry, Prince Henry Hospital, University of New South Wales, Sydney, Australia; University of Oxford Department of Psychiatry, Warneford Hospital, Oxford, United Kingdom; and Division of General Medicine, Brigham and Women's Hospital, Harvard University, Boston, Massachusetts. Abstract

The complexities of the chronic fatigue syndrome and the methodologic problems associated with its study indicate the need for a comprehensive, systematic, and integrated approach to the evaluation, classification, and study of persons with this condition and other fatiguing illnesses. We propose a conceptual framework and a set of guidelines that provide such an approach. Our guidelines include recommendations for the clinical evaluation of fatigued persons, a revised case definition of the chronic fatigue syndrome, and a strategy for subgrouping fatigued persons in formal investigations. We have developed a conceptual framework and a set of research guidelines to use in studies of the chronic fatigue syndrome. The guidelines cover the clinical and laboratory evaluation of persons with unexplained fatigue; the identification of underlying conditions that may explain the presence of chronic fatigue; revised criteria for defining cases of the chronic fatigue syndrome; and a strategy for subdividing the chronic fatigue syndrome and other unexplained cases of chronic fatigue into subgroups.

Background

The chronic fatigue syndrome is a clinically defined condition (1-4) characterized by severe disabling fatigue and a combination of symptoms that prominently features self-reported impairments in concentration and short-term memory, sleep disturbances, and musculoskeletal pain. Diagnosis of the chronic fatigue syndrome can be made only after alternate medical and psychiatric causes of chronic fatiguing illness have been excluded. No pathognomonic signs or diagnostic tests for this condition have been validated in scientific studies (5-7); moreover, no definitive treatments exist for the chronic fatigue syndrome (8). Recent longitudinal studies suggest that some persons affected by the chronic fatigue syndrome improve with time but that most remain functionally impaired for several years (9,10).

Issues in Chronic Fatigue Syndrome Research

The central issue in chronic fatigue syndrome research is whether the chronic fatigue syndrome or any subset of it is a pathologically discrete entity, as opposed to a debilitating but nonspecific condition shared by many different entities. Resolution of this issue depends on whether clinical, epidemiologic, and pathophysiological features convincingly distinguish the chronic fatigue syndrome from other illnesses.

Clarification of the relation between the chronic fatigue syndrome and the neuropsychiatric syndromes is particularly important. The latter disorders are potentially the most important source of confounding in studies of the chronic fatigue syndrome. Somatoform disorders, anxiety disorders, major depression, and other symptomatically defined syndromes can manifest severe fatigue and multiple somatic and psychological symptoms and are diagnosed more frequently in populations affected by chronic fatigue (11-13) and the chronic fatigue syndrome (14,15) than in the general population.

The extent to which the features of the chronic fatigue syndrome are generic features of chronic fatigue and deconditioning due to physical inactivity common to a diverse group of illnesses (16,17) must also be established.

A Conceptual Framework for Studying the Chronic Fatigue Syndrome

In the United States, 24% of the general adult population has experienced fatigue lasting 2 weeks or longer, with 59% to 64% of these people reporting no medical cause (18,19). In one study, 24% of primary care clinic patients reported having had prolonged fatigue (1 month) (20). In many persons with prolonged fatigue, fatigue persists beyond 6 months (defined as chronic fatigue) (21,22).

We propose a conceptual framework (Figure 1 below) to guide the development of studies relevant to the chronic fatigue syndrome. In this framework, in which the chronic fatigue syndrome is considered a subset of prolonged fatigue (one month), epidemiologic studies of populations defined by prolonged or chronic fatigue can be used to search for illness patterns consistent with the chronic fatigue syndrome. Such studies, which differ from case-control and cohort studies based on predetermined criteria for the chronic fatigue syndrome, will also produce much-needed clinical and laboratory background information. This framework also clarifies the need to compare populations defined by the chronic fatigue syndrome with several other populations in case-control and cohort studies. The most important comparison populations are those defined by overlapping disorders, by prolonged fatigue, and by forms of chronic fatigue that do not meet criteria for the chronic fatigue syndrome. Controls drawn exclusively from healthy populations are inadequate to confirm the specificity of chronic fatigue syndrome-associated abnormalities.

Proposed conceptual
framework for studies related
to CFS.

Need for Revised Criteria to Define the Chronic Fatigue Syndrome

The possibility that chronic fatigue syndrome study populations have been selected or defined in substantially different ways has made it difficult to interpret conflicting laboratory findings related to the chronic fatigue syndrome (23). For example, the North American chronic fatigue syndrome working case definition (1) has been inconsistently applied by researchers (24). This case definition is frequently modified in practice because some of the criteria are difficult to interpret or to comply with (25) and because opinions differ with regard to the classification of chronic fatigue cases preceded by a history of psychiatric illnesses (26,27).

Current criteria for the chronic fatigue syndrome also do not appear to define a distinct group of cases (28, Reyes M, et al. Unpublished data). For example, participants in the Centers for Disease Control and Prevention (CDC) chronic fatigue syndrome surveillance system (29) who met the chronic fatigue syndrome case definition did not substantially differ by demographic characteristics, symptoms, and other illness features from those who did not meet the definition (except by criteria used to place patients into one of our predetermined surveillance classification categories [Reyes M, et al. Unpublished data]). These findings indicate that additional subgrouping or stratification of study cases into more homogeneous groups is necessary for comparative studies.

Need for Clinical Evaluation Standards

Our experience suggests that fatigued persons often receive inadequate or excessive medical evaluations. In the CDC chronic fatigue syndrome surveillance system, all participants were clinically evaluated by a primary physician before enrollment. Subsequently, 18% were found to have a preexisting medical condition that plausibly accounted for their chronic fatiguing illness (Reyes M, et al. Unpublished data). These medical conditions were identified either from a single battery of routine laboratory tests done on blood specimens obtained at enrollment or from review of available medical records.

We believe that inappropriate tests are often used to diagnose the chronic fatigue syndrome in chronically fatigued persons. This practice should be discouraged.

Need for a Comprehensive and Integrated Approach

The complexities of the chronic fatigue syndrome and the existence of several obstacles to our understanding of it make a comprehensive and integrated approach to the study of the chronic fatigue syndrome and similar illnesses desirable. The purpose of the proposed guidelines in Figure 2 below is to facilitate such an approach.

Purpose
of
proposed guidelines-1

Purpose of proposed
guidelines-2

Definition and Clinical Evaluation of Prolonged Fatigue and Chronic Fatigue

Prolonged fatigue is defined as self-reported, persistent fatigue of 1 month or longer. Chronic fatigue is defined as self-reported persistent or relapsing fatigue of 6 or more consecutive months.

The presence of prolonged or chronic fatigue requires clinical evaluation to identify underlying or contributing conditions that require treatment. Further diagnosis or classification of chronic fatigue cases cannot be made without such an evaluation. The following areas should be included in the clinical evaluation.

1. A thorough history that covers medical and psychosocial circumstances at the onset of fatigue; depression or other psychiatric disorders; episodes of medically unexplained symptoms; alcohol or other substance abuse; and current use of prescription and over-the-counter medications and food supplements.
2. A mental status examination to identify abnormalities in mood, intellectual function, memory, and personality. Particular attention should be directed toward current symptoms of depressive or anxiety, self-destructive thoughts, and observable signs such as psychomotor retardation. Evidence of a psychiatric or neurologic disorder requires that an appropriate psychiatric, psychological, or neurologic evaluation be done.
3. A thorough physical examination.
4. A minimum battery of laboratory screening tests including complete blood count with leukocyte differential; erythrocyte sedimentation rate; serum levels of alanine aminotransferase, total protein, albumin, globulin, alkaline phosphatase, calcium, phosphorus, glucose, blood urea nitrogen, electrolytes, and creatinine; determination of thyroid-stimulating hormone; and urinalysis.

Routinely doing screening tests for all patients has no known value (20, 30). However, further tests may be indicated on an individual basis to confirm or exclude another diagnosis, such as multiple sclerosis. In these cases, additional tests or procedures should be obtained according to accepted clinical standards.

The use of tests to diagnose the chronic fatigue syndrome (rather than to exclude other diagnostic possibilities) should be done only in the setting of protocol-based research. The fact that such tests are investigational and do not aid in diagnosis or management should be explained to the patient.

In clinical practice, no additional tests, including laboratory tests or neuroimaging studies, can be recommended for the specific purpose of diagnosing the chronic fatigue syndrome. Tests should be directed toward confirming or excluding other etiologic possibilities. Examples of specific tests that do not confirm or exclude the diagnosis of the chronic fatigue syndrome include serologic tests for Epstein-Barr virus, retroviruses, human herpesvirus 6, enteroviruses, and *Candida albicans*; tests of immunologic function, including cell population and function studies; and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as single-photon emission computed tomography and positron emission tomography) of the head.

Conditions That Explain Chronic Fatigue

The following conditions exclude a patient from the diagnosis of unexplained chronic fatigue.

1. Any active medical condition that may explain the presence of chronic fatigue (31), such as untreated hypothyroidism, sleep apnea and narcolepsy, and iatrogenic conditions such as side effects of medication.
2. Any previously diagnosed medical condition whose resolution has not been documented beyond reasonable clinical doubt and whose continued activity may explain the chronic fatiguing illness. Such conditions may include previously treated malignancies and unresolved cases of hepatitis B or C virus infection.
3. Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features; bipolar affective disorders; schizophrenia of any subtype; delusional disorders of any subtype; dementias of any subtype; anorexia nervosa; or bulimia nervosa.

4. Alcohol or other substance abuse within 2 years prior to the onset of the chronic fatigue and any time afterward.
5. Severe obesity (32,33) as defined by a body mass index [body mass index = weight in kilograms/(height in meters)²] equal to or greater than 45.

Any unexplained physical examination finding or laboratory or imaging test abnormality that strongly suggests the presence of an exclusionary condition must be resolved before further classification.

Conditions That Do Not Adequately Explain Chronic Fatigue

The following conditions do not exclude a patient from the diagnosis of unexplained chronic fatigue.

1. Any condition defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, including fibromyalgia, anxiety disorders, somatoform disorders, nonpsychotic or nonmelancholic depression, neurasthenia, and multiple chemical sensitivity disorder.
2. Any condition under specific treatment sufficient to alleviate all symptoms related to that condition, and for which the adequacy of treatment has been documented. Such conditions include hypothyroidism for which the adequacy of replacement hormone has been verified by normal thyroid-stimulating hormone levels or asthma in which the adequacy of treatment has been determined by pulmonary function and other testing.
3. Any condition, such as Lyme disease or syphilis, that was treated with definitive therapy before development of chronic symptomatic sequelae.
4. Any isolated and unexplained physical examination finding, or laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition. Such conditions include an elevated antinuclear antibody titer that is inadequate to strongly support a diagnosis of a discrete connective tissue disorder without other laboratory or clinical evidence.

Major Classification Categories: Chronic Fatigue Syndrome and Idiopathic Chronic Fatigue

Clinically evaluated, unexplained chronic fatigue cases can be separated into either the chronic fatigue syndrome or idiopathic chronic fatigue on the basis of the following criteria.

A case of the chronic fatigue syndrome is defined by the presence of the following: 1) clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities; and 2) the concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during six or more consecutive months of illness and must not have predated the fatigue: self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities; sore throat; tender cervical or axillary lymph nodes; muscle pain; multijoint pain without joint swelling or redness; headaches of a new type, pattern, or severity; unrefreshing sleep; and postexertional malaise lasting more than 24 hours.

The method used (for example, a predetermined checklist developed by the investigator or spontaneous reporting by the study participant) to establish the presence of these and any other symptoms should be specified.

A case of idiopathic chronic fatigue is defined as clinically evaluated, unexplained chronic fatigue that fails to meet criteria for the chronic fatigue syndrome. The reasons for failing to meet the criteria should be specified.

Subgrouping and Stratification of Major Classification Categories

In formal studies, cases of the chronic fatigue syndrome and idiopathic chronic fatigue should be subgrouped before analysis or stratified during analysis by the presence or absence of essential variables, which should be routinely established in all studies. Further subgrouping by optional parameters can be performed according to specific research interests.

Essential Subgrouping Variables

1. Any clinically important coexisting medical or neuropsychiatric condition that does not explain the chronic fatigue. The presence or absence, classification, and timing of onset of neuropsychiatric conditions should be established using published or freely available instruments, such as the Composite International Diagnostic Instrument (34), the National Institute of Mental Health Diagnostic Interview Schedule (35), and the Structured Clinical Interview for DSM-III(R) (36).
2. Current level of fatigue, including subjective or performance aspects. These levels should be measured using published or widely available instruments. Examples include instruments by Schwartz and colleagues (37), Piper and colleagues (38), Krupp and colleagues (39), Chalder and colleagues (40), and Vercoulen and colleagues (41).

3. Total duration of fatigue.

Current level of overall functional performance as measured by published or widely available instruments, such as the Medical Outcomes Study Short Form 36 (42) and the Sickness Impact Profile (43).

Optional Subgrouping Variables

Examples of optional variables include:

1. Epidemiologic or laboratory features of specific interest to researchers. Examples include laboratory documentation (or self-reported history) of an infectious illness at the onset of fatiguing illness, a history of rapid onset of illness, or the presence or level of a particular immunologic marker.
2. Measurements of physical function quantified by means such as treadmill testing or motion-sensing devices.

Discussion

Several general points must be appreciated if these guidelines are to be used as intended. First, the overall purpose of the proposed conceptual framework and guidelines is to foster a more systematic and comprehensive approach toward the collection of data about the chronic fatigue syndrome and similar illnesses. As such, these tools are intended for use as standard references. However, none of the components, including the revised case definition of the chronic fatigue syndrome, can be considered definitive. These research tools will evolve as new knowledge is gained. Second, none of the provisions in these guidelines, especially the definition of idiopathic chronic fatigue and subgroups of the chronic fatigue syndrome, establish new clinical entities. Rather, these definitions were designed to facilitate comparative studies. Finally, general reference to these guidelines should not be substituted for clear and detailed methodologic descriptions when reporting studies. The lack of detailed information about the sources, selection, and evaluation of study participants (including controls), case definitions, and measurement techniques in reports of chronic fatigue syndrome research has contributed substantially to our current difficulties in interpreting research findings.

Several specific points about the clinical evaluation are worth emphasizing. The primary purpose of clinically evaluating a person with unexplained fatigue is to identify and treat any underlying and contributing factors. Such an evaluation should begin, whenever possible, before 6 months has elapsed. Because the particulars of any clinical evaluation will vary from patient to patient, our recommendations have been limited to those aspects of clinical evaluation that can be universally applied to all patients. With regard to the clinical psychiatric evaluation of fatigued persons, we consider a mental status examination to be the minimal acceptable level of assessment. Although a structured psychiatric evaluation of all patients with fatigue is highly desirable, we recognize the practical difficulties of implementing such a recommendation. The diagnosis of the chronic fatigue syndrome should not impede the treatment of coexisting disorders, notably depression.

Many conditions that are primary causes of chronic fatigue preclude the diagnosis of the chronic fatigue syndrome or idiopathic chronic fatigue. We presented principles for identifying such exclusionary conditions rather than listing them because of the range and complexity of human illnesses. In some instances, however, we identified specific exclusionary conditions. The presence of severe obesity makes the diagnosis of unexplained symptoms, such as fatigue or joint pains, extremely difficult.

We distinguished between psychiatric conditions for pragmatic reasons. It is difficult to interpret symptoms typical of the chronic fatigue syndrome in the setting of illnesses such as major psychotic depression or schizophrenia. More importantly, the care of these persons should focus on their chronic psychiatric disorder. On the other hand, we did not use other psychiatric disorders, such as anxiety disorders and less severe forms of depression, as a basis for exclusions. Such psychiatric conditions are highly prevalent in persons with chronic fatigue and the chronic fatigue syndrome, and the exclusion of persons with these conditions would substantially hinder efforts to clarify the role that psychiatric disorders have in fatiguing illnesses. This is a particularly important issue to resolve. These parts of the guidelines concur with the recommendation by a 1991 National Institutes of Health workshop (24) that chronic fatigue cases preceded by some, but not all, psychiatric syndromes can be classified as the chronic fatigue syndrome.

The revised case definition for the chronic fatigue syndrome is modeled on the 1988 chronic fatigue syndrome working case definition (1). The purpose of the revision was to address some of the criticisms (25) of that case definition and to facilitate a more systematic collection of data internationally. We dropped all physical signs as inclusion criteria because all of us agreed that their presence had been unreliably documented in past studies. The required number of symptoms was decreased from 8 to 4 and the list of symptoms was decreased from 11 to 8 because we agreed that multiple symptom criteria had increased the restrictiveness of the 1988 chronic fatigue syndrome working case definition without increasing the homogeneity of cases (Reyes M, et al. Unpublished data).

Whether to retain any symptom criteria other than chronic fatigue generated the most disagreement among the authors. Disagreement occurred between those who favored a more restrictive approach

(using several symptom criteria), as was done in the 1988 chronic fatigue syndrome working case definition, and those who favored a broader definition of chronic fatigue syndrome (using fewer symptom criteria) as was done in the Australian (3) and British (4) chronic fatigue syndrome case definitions. Those favoring multiple symptoms argued that use of multiple symptoms best reflected the empiric clinical sense of the chronic fatigue syndrome as a distinct entity. Others argued that no symptoms have been shown to be specific for the chronic fatigue syndrome (28) and that some studies suggest that a requirement for multiple symptoms biases the selection of cases toward those with psychiatric disorders (28, 44). Disagreement over this particular issue underscores the need to establish specific features of the chronic fatigue syndrome and the validity of any chronic fatigue syndrome case definition.

Developing an operational definition of fatigue was a problem because the concept of fatigue itself is unclear (45,46). In our conception of the chronic fatigue syndrome, the symptom of fatigue refers to severe mental and physical exhaustion, which differs from somnolence or lack of motivation and which is not attributable to exertion or diagnosable disease. We retained the requirement of 6 months' duration of fatigue to facilitate comparison with earlier cases of the chronic fatigue syndrome. The requirement for an "average daily activity below 50%" was eliminated because this level of impairment is difficult to verify.

We defined the condition of "idiopathic chronic fatigue" to focus attention on the need to clarify how other forms of unexplained chronic fatigue are related to the chronic fatigue syndrome.

Our strategy for subgrouping major classification categories depends upon the data made available from standardized evaluations of patients with chronic fatigue. Subgrouping by essential variables will encourage the collection of a body of core data. Additional subgrouping by optional variables will allow researchers considerable individual flexibility in defining specific subgroups to answer specific research questions.

The name "chronic fatigue syndrome" is the final issue that we wish to address. We sympathize with those who are concerned that this name may trivialize this illness. The impairments associated with chronic fatigue syndrome are not trivial. However, we believe that changing the name without adequate scientific justification will lead to confusion and will substantially undermine the progress that has been made in focusing public, clinical, and research attention on this illness. We support changing the name when more is known about the underlying pathophysiologic process or processes associated with the chronic fatigue syndrome and chronic fatigue.

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Appendix

The following are other members of the International Chronic Fatigue Syndrome Study Group:

National Institutes of Health: Ann Schluenderberg, ScD; University of Colorado, Denver, Colorado: James F. Jones, MD; Prince Henry Hospital of New South Wales, Sydney, Australia: Andrew R. Lloyd, MD, FRACP; King's College School of Medicine and Dentistry, London, United Kingdom: Simon Wessely, MRCP, MRC Psych; Polyclinic Medical Center and Penn State College of Medicine, Harrisburg, Pennsylvania: Nelson M. Gantz, MD; Texas A & M University Health Science Center and Scott & White Memorial Hospital, Temple, Texas: Gary P. Holmes, MD; University of Washington Medical Center, Seattle, Washington: Dedra Buchwald, MD; University of Toronto, Toronto, Canada: Susan Abbey, MD, FRCP(C); University of California, San Francisco, California, and Alta Bates Hospital, Berkeley, California: Jonathan Rest, MD; University of California, San Francisco, San Francisco, California: Jay A. Levy, MD; Food and Drug Administration, Rockville, Maryland: Heidi Jolson, MD, MPH; Lake Tahoe Medical Center, Incline Village, Nevada: Daniel L. Peterson, MD; University Hospital Nijmegen, Nijmegen, the Netherlands: Jan H.M.M. Vercoulen, PhD; Centro Regionale di Riferimento Oncologico, Aviano, Italy: Umberto Tirelli, MD; Karolinska Institute at Huddinge University Hospital, Stockholm, Sweden: Birgitta Evengard, MD; New Jersey Medical School, Newark, New Jersey: Benjamin H. Natelson, MD; Division of Viral and Rickettsial Diseases, National Center for Infectious Diseases, Centers for Disease Control and Prevention, Atlanta, Georgia: Lea Steele, Michele Reyes, and William C. Reeves, MD.

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Current Author Addresses

Drs. Fukuda and Dobbins: Mailstop A15, Division of Viral and Rickettsial Diseases, National Center for Infectious Diseases, Centers for Disease Control and Prevention, 1600 Clifton Road, Atlanta, GA 30333.

Dr. Straus: Clinical Center Room 11N228, Laboratory of Clinical Investigation, National Institutes of Health, 9000 Rockville Pike, Bethesda, MD 20892.

Dr. Hickie: School of Psychiatry and Department of Infectious Diseases and Immunology, Prince Henry Hospital, University of New South Wales, Little Bay, NSW, 2036, Australia. Dr. Sharpe: University of Oxford, Department of Psychiatry, Warneford Hospital, Oxford, OX3 7JX, United Kingdom.

Dr. Komaroff: Division of General Medicine, Brigham and Women's Hospital, 75 Francis Street, Boston, MA 02115.

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Profiles

Most people will not become interested or active in efforts surrounding a medical condition until they can imagine what it would be like to have it. Profiles about life with chronic fatigue and immune dysfunction syndrome (CFIDS) are important because they give those unfamiliar with the illness an accurate picture of the toll it takes on individual lives.

Sharing personal stories also gives patients a voice. Award-winning author and person with CFIDS (PWC) Floyd Skloot says, "Some of us have been silent because of the hopelessness of overcoming both symptoms and perceptions... We need to share our experience, to say what it is like to be a PWC. The act of communication serves both speaker and hearer."

Many PWCs, including several well-known [celebrities with CFIDS](#), have spoken out about their experiences in order to advance knowledge and understanding of the illness.

The CFIDS Association of America gives PWCs from all walks of life a chance to share stories and coping tips in [The CFIDS Chronicle](#), a quarterly magazine for the patient community. The Association has also created a new publication, [Snapshots of CFIDS](#), which provides compelling profiles of CFIDS patients and the impact the illness has had on their careers, education, families, and hopes for the future.

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Profiles: Celebrity

Well-known public figures with CFIDS include Michelle Akers, Amy Peterson, Keith Jarrett, and Jackson Parkhurst. These individuals have been willing to raise awareness of this devastating illness by speaking out about how it has affected their lives and careers.

[Michelle Akers](#), star of the U.S. women's soccer team, has acknowledged publicly the extraordinary adjustments she has made in her life to be able to play despite her CFIDS, and that has led to extensive media coverage of the illness. In August of 2000, Akers stepped down from the U.S. Olympic team due in part to "a weariness of the constant maintenance of CFIDS necessary in order to be able to perform at the international level."

Other athletes have struggled with CFIDS, including speedskater [Amy Peterson](#), who was featured in a March/April 1998 CFIDS Chronicle cover story. Peterson was a medal winner in the 1992 and 1994 Winter Olympics, but fell ill in 1995 with CFIDS and spent the next few years trying to build back up to her former competitive level.

[Keith Jarrett](#), one of the world's most popular jazz pianists, has spent more than four years living with CFIDS. He became ill during a 1996 concert tour in Italy, cancelled all his concert dates, and went home to rural New Jersey to focus on getting better. He has now begun performing and recording again, but acknowledges that he is still recovering.

Former symphony conductor [Jackson Parkhurst](#) is still hoping for recovery. In the early 1990's, Parkhurst was conducting 65 to 70 concerts a year for the North Carolina Symphony. He developed CFIDS in 1993, and a severe exacerbation of the illness during a concert in 1995 made him realize that he could no longer keep conducting.

See the [media coverage](#) section of www.cfids.org for recent articles about celebrities who have CFIDS.

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Q. What causes CFIDS?

A. No single cause of the illness has been determined. Current research indicates that there are likely multiple triggers resulting in the same set of [symptoms](#). Many people report that their symptoms began following a flu-like illness; however, some people report that the disorder began spontaneously and symptoms became gradually worse. Physical trauma, genetics, immunological conditions, and possibly severe emotional distress appear to be related to some cases.

Q. Is there a diagnostic test for CFIDS?

A. No, there is no blood, urine, or imaging test to diagnose CFIDS. The keys to [diagnosis](#) are identifying a characteristic pattern of symptoms and excluding other possible causes.

Q. Is there a cure for CFIDS?

A. No, there is no curative [treatment](#) for the illness. However, there is a range of symptomatic and supportive therapies that are helpful.

Q. What are the symptoms of CFIDS?

A. According to the 1994 International [Case Definition](#) the symptoms include: fatigue lasting for six months or longer that significantly affects lifestyle; in addition, four or more of the following symptoms must be present [along with the debilitating fatigue]:

- Impaired memory or concentration
- Sore throat
- Muscle pain
- Multi-joint pain
- Tender lymph nodes in the armpit and neck
- Headaches of new type, pattern, or severity
- Post-exertional malaise (lasting more than 24 hours)
- Sleep difficulties / unrefreshing sleep

Q. How do I get a diagnosis?

A. A [questionnaire](#) designed to help people determine if they might have CFIDS is available on this site. It may be beneficial for people to take a few minutes to complete this informational survey and discuss the results with their primary care providers. The 1994 International [Case Definition](#) is the prevailing document used for diagnosis; even though it was developed as a research case definition, providers use it to help with diagnosis. CFIDS is a largely misunderstood illness and some health care providers view the illness with skepticism. If this is true with your provider, it may be necessary to find a physician who is CFIDS "friendly" and knowledgeable.

Q. How do I find a doctor who is knowledgeable about CFIDS?

A. Start by reading The CFIDS Association of America's brochure, "[Choosing a Doctor.](#)" A reliable source of referral often comes from area [support groups](#) where people share information about their experiences as well as health care providers who are CFIDS-knowledgeable. A support group listing is also available from the [U.S. Centers for Disease Control and Prevention](#).

Q. Is CFIDS a psychological disorder?

A. No. All chronic illnesses have significant medical, psychological, and social components. CFIDS is not simply a form of [depression](#) or anxiety, although these may result from having a chronic, debilitating illness.

Q. How many people have CFIDS and who gets it?

A. A recent [community-based survey](#) estimates that over 800,000 U.S. adults and children have the illness, yet, only about 10% have been diagnosed. Persons of all socioeconomic levels, races, sexes, ages, and geographic locations have CFIDS. The myth that CFIDS is the "yuppie flu" and is most prevalent in young, well-to-do, professional, white females has not been supported by research. Recent community studies show that, in reality, persons of color and lower income are at greater risk for CFS.

Q. How do I explain CFIDS to my friends, family, and employer?

A. Living with a chronic illness creates issues for all relationships of the person who is ill. Support and help is available [for you](#) and [your family](#) through The CFIDS Association of America. Local [support](#)

[groups](#) provide invaluable help in learning to cope with the many life changes that can occur when a person has CFIDS.

Q. Where can I find a support group?

A. The CFIDS Association of America can provide interested persons with [support group contacts](#) in their area. It also serves as an Internet resource, providing support and valuable information about the illness as well as links to other CFIDS sites.

Q. Will exercise, bed rest, or diet changes help?

A. There are treatments that can help ease symptoms. These include various medications that are given to help with specific symptoms, such as sleep disturbances or pain; and alternative/complementary therapies such as massage, yoga, or Tai Chi. For more information on treatment, see the [treatment](#) page.

- A regular, gentle exercise program that is specifically designed for the ill person can be beneficial. Excessive activity may aggravate symptoms and a hallmark symptom of CFIDS is exercise intolerance. It's important for person with CFIDS to learn to [pace themselves](#).
- Bed rest may temporarily alleviate symptoms, but doesn't improve the chance for recovery. If continued, bed rest may actually make symptoms worse and can result in deconditioning and the development of other conditions.
- Because many persons with CFIDS have digestive problems (nausea, pain, irritable bowel syndrome) maintaining adequate nourishment can be a challenge. Many fad diets call for an imbalanced food intake and can create poor nutritional status. [Food intolerances](#) are also a problem for a significant number of people with CFIDS. Help is available by speaking with your health care provider and/or a registered dietitian, and on this Web site.

Q. How long will it take to recover?

A. It is not possible to predict recovery. About one-third of persons with CFIDS recover almost fully, but no one knows why. Some people recover in small to moderate degrees, while others recover minimally, if at all. Still others have progressively worse symptoms over time. Very little data exists about recovery rates for CFIDS, but researchers are actively investigating this question. Statistically, the best chance of recovery occurs in the first five years of the illness.

Q. Should people with CFIDS donate blood?

A. The Association recommends that CFIDS patients refrain from donating blood, bone marrow or organs, as it is currently unknown whether or not this is a safe practice since the contagion issue has not been resolved. Additionally, donating blood may not be safe for persons with CFIDS (PWCs), as research has shown that many PWCs have low blood volume and other vascular problems, and removing additional blood could provoke a relapse.

Q. Can people with CFIDS continue working?

A. It is possible, but is highly individualized and dependent on symptom severity and the demands of a given job. There is a wide spectrum of disability ranging from people who can work a few part-time hours to those who are unable to work at all. Some persons who experience mild symptoms are able to work full time. Community-based studies report that approximately 53% of persons with CFIDS continue to work. Whenever possible, people should be encouraged to continue working because of its benefits to self-esteem and economic security. Decisions about changing employment status need to be considered carefully, obtaining as much information as possible regarding continuation of insurance and disability benefits.

Q. Are people with CFIDS eligible for Social Security and long-term disability benefits?

A. Yes. Like any other medically certified illness, sickness benefits or disability allowances are an important part of ensuring financial stability for people who are disabled by CFIDS. For more information about disability benefits, see the [legal issues](#) page on this site.

Q. I get very discouraged at times when I look back at the changes in my life since CFIDS. What can I do?

A. These feelings are a common part of coping with a chronic illness. Talk with your primary care provider and/or find a therapist, minister, or support group with whom you can voice your feelings. [Cognitive behavioral therapy](#) is a method that has been used with some success to help persons with CFIDS cope with the psychological aspects of having this illness. Although periods of sadness that last a day or two are normal, extended periods of feeling sad, hopeless, and "down" are troublesome; it's crucial to seek medical help during these times because co-existing depression with CFIDS can make people feel even worse.

Q. What is being done about CFIDS?

A. [Federal agencies](#), such as National Institutes of Health and U.S. Centers for Disease Control and Prevention, along with organizations like The CFIDS Association of America, encourage and support CFIDS research and education. [Advocacy](#) efforts by The CFIDS Association of America provide on-going action that draws the attention of scientists and governmental agencies to CFIDS.

Q. What can I do to help?

A. Depending on the severity of your symptoms, you may consider becoming a participant in a [research study](#) or wish to [help educate](#) others about the illness. [Starting a support group](#) in your area if one does not exist, or becoming an active part of an [existing support group](#) are other ways to help. You may be able to use your computer, telephone, or writing skills to communicate with others about the illness. Joining The CFIDS Association of America and/or making a financial donation to aid in research and public awareness are also important ways to assist. For more information about [how you can help](#), explore our site or [contact us](#).

Q. What is The CFIDS Association of America?

A. [The CFIDS Association](#) is a not-for-profit, charitable agency and the largest organization dedicated to conquering CFIDS. Its membership exceeds 20,000 people. The Association has invested over \$12 million dollars in CFIDS education, public policy, and research since it was formed in 1987.

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