What is CFIDS?

CFIDS (chronic fatigue and immune dysfunction syndrome) is also known as CFS (chronic fatigue syndrome), CEBV (chronic Epstein-Barr virus), M.E. (myalgic encephalomyelitis), "yuppie flu" and many other names. It is a complex illness characterized by incapacitating fatigue (experienced as exhaustion and extremely poor stamina), neurological problems and a constellation of symptoms that can resemble other disorders, including: mononucleosis, multiple sclerosis, fibromyalgia, AIDS-related complex (ARC), Lyme disease, post-polio syndrome and autoimmune diseases such as lupus. These symptoms tend to wax and wane but are often severely debilitating and may last for many months or years. All segments of the population (including children) are at risk but women under the age of 45 seem to be the most susceptible.

• What causes CFIDS?

Research suggests that CFIDS results from a dysfunction of the immune system. The exact nature of this dysfunction is not yet well defined, but it can generally be viewed as an up-regulated or overactive state (which is responsible for many of the symptoms). Ironically, there is also evidence of some immune suppression in CFIDS; patients exhibit certain down-regulated signs. For example, in many patients there are functional deficiencies in natural killer cells (an important component of the immune system responsible for fighting viruses).

Based on physical and laboratory findings, many scientists believe that viruses are associated with CFIDS and may be directly involved in causing the disease. Since the discovery (or rediscovery) of CFIDS in the United States in the mid-1980s, several viruses have been - and continue to be - studied to determine what, if any, part they play in the disease. These include enteroviruses, herpesviruses (especially human herpesvirus-6 or HHV-6) and newly discovered retroviruses. In the first few years of this research, it was thought that the Epstein-Barr virus (EBV), a herpesvirus that causes mononucleosis, was the cause of this syndrome. However, researchers now believe that EBV activation (when it exists) is a result or complication of CFIDS rather than its cause. To date, no virus has been conclusively shown to be an essential element of CFIDS.

Accordingly, research efforts are still directed toward identifying and isolating the fundamental agent(s) responsible for triggering immune system disruption in persons with CFIDS (PWCs). Additionally, there are on-going studies of immunologic, neurologic, endocrinologic and metabolic abnormalities and risk factors (such as genetic predisposition, age, sex, prior illness, other viruses, environment and stress) which appear to play an important role in the development and course of the illness. For further information see The CFIDS Chronicle which reports extensively on many aspects of CFIDS research and/or call The CFIDS Information Line (900/8962343).

• How is CFIDS diagnosed?

Many physicians have based their diagnosis of CFIDS on a Working case definition developed for research use by the Centers for Disease Control (CDC) and published in the March 1988 Annals of Internal Medicine. This definition, however, did not effectively distinguish between CFIDS patients and other groups of people with fatiguing illnesses. In 1993, a working group of internationally recognized CFIDS researchers was assembled by CDC to revise the case definition. "The Chronic Fatigue Syndrome: A Comprehensive Approach to Its Definition and Study was published in the December 15, 1994 issue of Annals of Internal Medicine. (This article is available from the Association. Please see item 4140 on the list of "Educational Materials" to order.)

Guidelines for the evaluation and study of CFIDS as outlined in the revised case definition follow: A thorough medical history, physical examination, mental status examination and laboratory tests must be conducted to identify underlying or contributing conditions that require treatment. Diagnosis or classification cannot be made without such an evaluation. Clinically evaluated, unexplained chronic fatigue cases can classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. 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.
2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi joint pain without joint swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have predated the fatigue. Although the CDC case definition is in some sense "official" (and legitimizes the illness), it is considered provisional because it is based on the exclusion of other diseases and on symptoms which can be produced by other diseases. Pioneering CFIDS clinicians and researchers are making great strides in identifying specific objective markers for diagnosing CFIDS and for assessing patient treatment response. As reported in this and past issues of The CFIDS Chronicle (see especially, "CFIDS: The Diagnosis of a Distinct Illness," September 1992), physicians and scientists are developing an array of tests which are increasingly sensitive to and specific for CFIDS. As the cause and mechanism of this disease become clear, so will the clinical and laboratory parameters which define CFIDS. Ultimately, conclusive diagnostic standards will be developed and accepted.

Unfortunately, many physicians are not very familiar with CFIDS and have difficulty diagnosing it. Others still do not even know that the illness exists. As a result, PWCs are often misdiagnosed, sometimes as having a psychosomatic or affective disorder because such conditions are also diagnosed by exclusion in many cases.

• What other symptoms are commonly experienced in CFIDS?

PWCs experience symptoms which tend to be individualistic and to fluctuate in severity. The primary eight symptoms described in the CDC's revised case definition are listed above. Further symptoms common to CFIDS could include other cognitive function problems (such as spatial disorientation and impairment of speech and/or reasoning); visual disturbances (blurring, sensitivity to light, eye pain, frequent prescription changes); psychological problems (depression, anxiety, panic attacks, personality changes, emotional lability); chills and night sweats; shortness of breath; dizziness and balance problems; sensitivity to heat an cold; intolerance of alcohol; irregular heartbeat; abdominal pain, diarrhea, irritable bowel; low temperature; numbness o or burning in the face or extremities; dryness of the mouth and eyes (sicca syndrome); hearing disorders or sensitivity; menstrual problems including PMS and endometriosis; hypersensitivity of the skin; chest pains; rashes; allergies and sensitivities to odors, chemicals and medications; weight changes without changes in diet; hair loss; light-headedness — feeling "in a fog"; fainting; muscle twitching; and seizure

• How can CFIDS be treated and what is the prognosis?

No primary therapy has been proven to cure CFIDS. Son symptoms can frequently be alleviated by prescription drugs but these must be carefully tailored to the needs of each individual and often must be taken in unusually low dosages (An experimental drug has been tested in limited clinical trials. While the results were encouraging, further trials mus be conducted and evaluated before the drug can be approved Also, avoidance of environmental irritants and certain foods