

What do the terms ME, FM, EBV, CFS, CFIDS, AACFS and IACFS, CFSCC, CFSAC, CDC, NIH, SOK, ICD, ICD-CM, PVFS, PPS, PWC mean?

ME- In 1956, Dr. Melvin Ramsey, of England, coined the term Myalgic Encephalomyelitis (ME) while investigating an illness that had “CFIDS-like” properties. The name was first published in the United Kingdom in the Lancet.

FM- In 1976, Fibromyalgia (FM) was first coined as a term, even though the illness had been believed to have been around for a long time. In 1990, The American College of Rheumatology developed diagnostic criteria for doing FM research and the term caught on.

EBV- During the mid 1980’s, many thought the outbreaks of illness at Incline Village, Nevada were Epstein Bar Virus (EBV). Hence, CFS started life during the later part of the 20th century as EBV. EBV is a very common virus, found in a large percentage of folks around the world. In a child, it really doesn’t manifest illness. In a teenager, if it is their first exposure, it is mononucleosis. Active EBV in adults can be a single cause or combined with other processes and can become a serious illness. By 1988, at least four studies had been done that could not connect EBV to CFS.

CFS- In 1988, the Centers for Disease Control and Prevention (CDC) published their definition of the illness in Annals of Internal Medicine, naming it Chronic Fatigue Syndrome (CFS). To say the name was a bit dismissive is an understatement. [Visit the CDC CFS website](#) .

CFIDS ("cee-fids") - By the 1990’s, patient groups and patients started calling the disease Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) to reflect the immune component of the illness. However, the formal name for research in America is still CFS.

AACFS- The American Association for Chronic Fatigue Syndrome (AACFS) ran its first national conference in 1998. It went on to run a number of conferences.

IACFS- In 2006, the organization of AACFS officially changed its name to the International Association for Chronic Fatigue Syndrome (IACFS) to reflect how far and wide this illness was. Today, it runs a biannual international scientific conference that brings together researchers from all over the world. [Visit the IACFS/ME website](#) .

CFSCC - In 1999, the Chronic Fatigue Syndrome Coordinating Committee (CFSCC) was formed and its goal was to act as a liaison to the Department of Health and Human Services (DHHS) to offer advice on how to handle CFS. The committee was made up of government physicians and non-government physicians, who were actually in the trenches either treating patients or researching CFS. Recommendations were made to the Assistant Secretary of Health and Human Services which were passed on to the Secretary of Health and Human Services. [Visit the Department of Health and Human Services website](#) .

CFSAC ("cif-sack") - In 2003, The Chronic Fatigue Syndrome Coordinating Committee (CFSCC) changed its name to the Chronic Fatigue Syndrome Advisory Committee (CFSAC). The CFSAC is specifically convened for "inter-agency coordination" from the CDC and NIH as well as with public input.

CDC- Centers for Disease Control and Prevention (CDC), located in Atlanta, Georgia, is the government agency responsible for public health and answers to the Department of Health and Human Services (DHHS). CDC is called upon to investigate outbreaks, conduct research, develop health policies, and provide leadership and training among some of its many duties. [Visit the CDC homepage](#)

NIH- National Institutes of Health, located in Bethesda, Maryland, is made up of many Institutes. Their mission statement reads "NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce the burdens of illness and disability." The various Institutes foster creative discoveries, develop innovative research, which, when applied, improves health. They have a rich history. [To read more about the history of the NIH, visit their website](#) . They too are a division of the Department of Health and Human Services. [Visit the main website for the NIH](#)

SOK- In April, 2011 National Institutes of Health (NIH) hosted the State of the Knowledge

(SOK) workshop on CFS. At this time, NIH started using the term ME/CFS rather than just CFS. ME is a recognized illness in the rest of the world except for America. So, this was an effort to combine the two names. There is some controversy over this from some patient groups. While some feel ME should stand alone others feel it is a good move to combine them.

The CDC still uses the term CFS. Not all government agencies are on the same page. This, in part, is due to politics, definition, advocacy efforts and whatever goes on behind the curtain.

ICD - The United States and countries across the world classify illnesses using an official coding system called the International Classification of Diseases (ICD) developed and administered by the World Health Organization (WHO). With the newest modification about to take place, the rest of the world will be upgrading to version ICD 11, while the United States will be upgrading from version 9 to version 10.

ICD-CM - Individual nations can modify the ICD codes in order to better accommodate their needs, but only with permission from the WHO. In the U.S., it stands for International Classification of Diseases- Clinical Modification (ICD-CM). Again, there is controversy as to where to list CFS. The importance of this is due to the fact the ICD codes are used in many types of health records: for billing purposes; for Medicare and Medicaid; for disability insurance; for mortality and morbidity statistics.

PVFS- Post Viral Fatigue Syndrome (PVFS) was another term, not as commonly used, which was interspersed with CFS, sometimes because the belief was that CFS patients' illness was triggered by a virus .

PPS- Post Polio Syndrome (PPS) During the late 1980's, patients who had "recovered" from polio were complaining of the type of fatigability that CFS patients had. There was a flurry of research on polio patients and by the late 1990's, interest and money had diminished. What came out of the research was the understanding that as polio patients got older, the "good" arm or leg was wearing out from overworking. No easy answer to help them was found.

GWS- Gulf War Syndrome (GWS) became an issue in the 1980's. It took the government about 17 years to acknowledge that GWS really did exist. Many of the GWS patients got diagnosed with CFS.

PWC- Patients with Chronic Fatigue Syndrome (PWC) was a term coined by some patient groups and advocacy persons during the 1990's. It has fallen by the wayside, but every now and then it shows up in an article. If you read PWC, now you know what it means.

NIDS- Neuro-Immune Dysfunction Syndrome (NIDS) was founded by Dr. Michael Goldberg, of California. Dr. Goldberg is a pediatrician whose wife developed Chronic Fatigue Syndrome. He began to see a pattern of neuro-immunity issues in both his CFS patients and his pediatric autistic patients. He went on to develop an approach to treating his population and founded the Neuro-Immune Dysfunction Syndrome organization. [Visit the main website for NIDS](#) .

MassCFIDS/ME & FM Association- started in 1983, and incorporated in 1985, this patient organization is run by an all volunteer staff and is the oldest patient group in the country. The name of the organization has morphed with time to reflect the changing times. It started life as MasseBV, then CFIDS, then ME and FM were added to reflect our patient population. This organization is at another crossroads of change. The Board of Directors takes their jobs very seriously in guiding MassCFIDS/ME & FM. Changing the name to CFS did not make any sense. Dropping CFS for ME also did not make sense. Until the dust settles and the ICD codes are finalized, and the CDC and NIH can come to some agreement on the name, the Board has decided to keep the name of the organization as it stands for the time being.