

**HOW TO APPLY FOR
SOCIAL SECURITY DISABILITY BENEFITS
IF YOU HAVE
CHRONIC FATIGUE SYNDROME
(CFS/CFIDS)
MYALGIC ENCEPHALOPATHY (ME)
and
FIBROMYALGIA (FM)**

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The Massachusetts CFIDS/ME & FM Association serves as a clearinghouse for information about Chronic Fatigue Immune Dysfunction Syndrome/Chronic Fatigue Syndrome (CFIDS/CFS), Myalgic Encephalopathy (ME) and Fibromyalgia Syndrome (also known as Fibrositis).

This book is intended to give people ideas as to what is involved in qualifying for some programs which provide disability or other benefits. The book is not intended to cover all programs and is not intended to be a substitute for the advice of a competent attorney. This book reflects an accumulation of opinions and experiences of different individuals and advocates and nothing more. For legal advice it is imperative to consult with an attorney or qualified legal advocate of your own choosing. Further, the law is fluid and what applies in Massachusetts at a particular time may not apply elsewhere and visa-versa. Moreover, what is valid today in this booklet when it goes to press may not be valid after it is published. The Massachusetts CFIDS/ME & FM Association, Kenneth Casanova, and any and all persons who participated in authoring, contributing to, or producing this booklet assume no responsibility for any use of this booklet by its readers or for any results or consequences of such usage or further, for any other activity which occurs from the reading of the booklet or the application of its content.

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HOW TO USE THIS BOOK

The book is long because there are so many aspects of the Social Security Disability process, and each requires detailed discussion in order that you will be well-informed so that you can make the best decisions possible.

Fortunately, I hope, this book is well-organized. The book is not meant to be read through entirely. You should use the Table of Contents to find what you need to know according to what step of the Social Security Disability process you are in.

If you want to know if you are potentially eligible to apply, start by reading the Introduction. If you decide to apply, then you must read the main body of the booklet after the Introduction, as well as Appendix II and Appendix IV. If you already have an up-to-date and well-documented CFS diagnosis, you may want to skip the section on “Obtaining a CFS Diagnosis.”

It is very important that everyone read, no matter what stage you’re involved in, the section on the **1999 CFS Ruling**, because it’s so important.

If your doctor needs help in knowing how to diagnose CFIDS or FM, give him/ her Appendix I.

If you reached the Administrative Law Judge hearing stage, turn to Appendix III. If you’re getting reviewed, turn to Appendix VI.

If you are a lawyer and are looking for positive legal precedents for winning CFS or FM Disability claims, see Appendix V.

If you are applying for disability through your employer, read Appendix VII and Appendix IV. You should also look at the Resource Section.

You get the idea: **Navigate using the Table of Contents.**

Just to let you know. This booklet has been an ongoing project since the early 1990s. It contains the advice of lawyers, disability specialists, and the experience of many disability claimants. I can say, from the reports of patients with CFIDS, that it has helped many. I hope it helps you.

Ken Casanova

APPENDIX V

Landmark Federal Court Decision Establishes Right of Persons Diagnosed with and Disabled by CFIDS to Obtain Social Security Disability Benefits

On November 30, 1993, the United States Court of Appeals, 10th Circuit, handed down a landmark court decision, establishing and enforcing the right of disabled individuals diagnosed with CFIDS to collect Social Security Disability benefits. The decision, *SISCO vs. the United States Department of Health and Human Services* (10 F.3d 739 [10th Circuit 1993]) constitutes an important recognition by the federal courts of the plight of CFIDS patients. The decision will have the effect of requiring the Social Security Administration to more clearly recognize CFIDS as a legitimate disabling illness and will cause the Social Security Administration to award benefits more fairly and with less difficulty. The decision will be an important legal tool for attorneys and legal advocates in establishing CFIDS disability claims before Administrative Law Judges (ALJ), and when necessary, before the federal courts.

Specifically, the ruling reversed the denial of Social Security benefits to a clearly disabled person suffering from CFIDS by an Administrative Law Judge and by a Federal District Court. The Appeals Court made two major findings with regard to Social Security Disability CFIDS Claims:

(1) The Court found that Social Security cannot deny a CFS Disability Claim because the CFS diagnosis cannot be definitively confirmed or verified by one or more laboratory tests. The Court found that, at the present time, there are no laboratory tests which can be used to establish or verify a CFS diagnosis. The Court found that the present medical consensus that CFS is properly diagnosed by a process of excluding other illnesses and by the presence of a characteristic symptom profile must be accepted by Social Security as the proper method for establishing a CFS diagnosis. A diagnosis properly established by this method cannot be rejected by Social Security simply because laboratory tests are not available to definitively establish the diagnosis.

(2) The Court also determined that a physician's diagnosis of CFS which is based on proper diagnostic method cannot be rejected simply because, in the past, one or more of a patient's physicians have been unable to diagnose the patient's illness (particularly if the earlier failures to diagnose do not contradict the subsequent diagnosis of CFIDS.) The Court recognized that CFS has only recently been validated by the medical community, and that in the past many physicians were not sufficiently informed to make a diagnosis. Moreover, the Court found that the Administrative Law Judge, contrary to the evidence presented, minimized the severity and the disabling effects of the patient's illness. The Court further found that the Administrative Law Judge distorted the patient's testimony. The findings of the Court, in this regard, will serve as an instruction to the Administrative Law Judges and the courts to evaluate CFS claims based on the evidence presented.

Here follows some of the more pertinent language of the decision:

The most glaring misconception is the ALJ's belief that the language in Paragraph 223(d)(5)(A) of the Social Security Act (SSA) requiring proof of a disability by "medically acceptable clinical or laboratory diagnostic techniques" means that a disability is covered by the Act only if it can be conclusively diagnosed by a "laboratory-type" test... Indeed, the plain meaning of the language simply indicates that a claimant's disability must be diagnosed through the use of a technique, either clinical or

laboratory, that has been accepted by the medical community.

At this point there is no "dipstick" laboratory test for chronic fatigue syndrome... Furthermore, since its "discovery" a few years ago, numerous cases involving chronic fatigue syndrome have been adjudicated across the country and we are unable to find any suggestion in these cases that this disease - or any other disease - is per se excluded from coverage because it cannot be conclusively diagnosed in a laboratory setting...

The "operational" diagnosis technique used by the medical community at the present time involves testing, the matching of a detailed list of symptoms, the painstaking exclusion of other possible disorders, and a thorough review of the patient's medical history... Although this type of clinical diagnostic method may not be as dramatic or impressive to a layman as a "dipstick" laboratory test, it is the technique presently used and accepted by the medical community. Section 223(d)(5)(A) of the Social Security Act does not require more...

Moreover, because chronic fatigue syndrome is diagnosed partially through a process of elimination, an extended medical history of "nothing-wrong" diagnoses is not unusual for a patient who is ultimately found to be suffering from the disease... Finally, in a purely linguistic sense, an early report that, "I am unable to find the cause," does not contradict a later report that, "I have now found the cause." These statements together demonstrate an evolution rather than a contradiction."

Additional federal court decisions granting CFS and Fibromyalgia disability claims:

1. *Rose v. Shalala*, 34 F.3d13(1st Cir. 1994) A landmark decision supporting the right of disabled persons with CFIDS to receive Social Security Disability benefits.
2. *Mongrelize v. Baxter Trevino* Long Term Disability Benefit Plan, 1995 WL 34268 (9th Cir. (Cal.)) Important decision upholding CFIDS claim against employer disability carrier; carrier claimed that the person with CFIDS had a psychological disorder and was not entitled to continuing long-term benefits.
3. *Preston v. Secretary of Health and Human Services* 854 F. 2d 815 (6th Cir. 1988) Precedent setting decision upholding right of claimant with disabling fibromyalgia to collect Social Security disability benefits.