

**HOW TO APPLY FOR
SOCIAL SECURITY DISABILITY BENEFITS
IF YOU HAVE
MYALGIC ENCEPHALOMYELITIS/
CHRONIC FATIGUE SYNDROME
(ME/CFS)**

With Additional Information on Applying for Benefits
If You Have Fibromyalgia

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Massachusetts ME/CFS & FM Association
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DISCLAIMER

The Massachusetts ME/CFS & FM Association serves as a clearinghouse for information about 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 ME/CFS&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 very 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.

A sick individual will find it difficult to read through this booklet except during times when they are feeling better ; this book is meant to be read in steps according to what you need to know, according to what step of the Social Security process you are on.

Applying for Social Security Disability is often a long-haul process, so take it one step at a time, and learn what you need to at each stage. Just learn at your own pace – or if you have a family member or friend who can help you learn from this book, all the better.

Obviously this book is meant to be comprehensive – so as not to leave out anything that would give you the best chance to win your case.

The book is not meant to be read through entirely. You should use the Table of Contents to find the information you need as follows:

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 I for ME/CFS; and Appendix III for fibromyalgia. ***Also you should absorb Appendix IV, since it gives you a wealth of information on how to document the illness.*** If you already have an up-to-date and well-documented ME/CFS diagnosis, you may want to skip the section on “Obtaining a ME/CFS Diagnosis.”

It is very important that everyone read, no matter what stage you’re involved in, Appendix I on the **2014 Social Security ME/CFS Ruling** because it’s so important. Also, you must read the Social Security Guidance for providing medical evidence: **“Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome”**, and make sure your physician(s) have a copy.

For Fibromyalgia sufferers many sections of this booklet apply generally to fibromyalgia disability applications. There are also sections that apply specifically to FM, particularly the **2012 Fibromyalgia Social Security Ruling** (see Appendix III.)

If you reached the Administrative Law Judge hearing stage for ME/CFS, turn to Appendix I, IV and V. If you’re getting reviewed when you are on Disability, turn to Appendix VIII.

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

If you are applying for disability through your employer, read Appendix IX and Appendix IV. You should also look at the section on Long-Term Employer Disability on our website: <https://www.massmecfs.org/disability>.

Also, on our website we have an entire disability section with many important articles relating to many different aspects of needed assistance for those who lose employment because of the illnesses. The disability home page is at <https://www.massmecfs.org/disability>

Also, there is a specific section on Social Security disability with articles and information that are an important supplement to this Booklet. Applicants should check this section out at <https://www.massmecfs.org/social-security-disability>

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 ME/CFS, that it has helped many. I hope it helps you.

Ken Casanova

Appendix VII

Landmark Federal Court Decision Establishes Right of Persons Diagnosed with and Disabled by CFS 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 CFS 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 ME/CFS patients. The decision will have the effect of requiring the Social Security Administration to more clearly recognize CFS 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 CFS disability claims before Administrative Law Judges, and when necessary, before the federal courts. (Of course, since then, the 2014 Ruling has improved the understanding of CFS by the Social Security Administration.)

Unfortunately some States Disability Determination Services may not be fully aware of the 2014 Ruling, nor may even some Administrative Law Judges. The claimant's attorney and doctor should reference the Ruling in their briefs and letters.

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

3) The Court recognized that CFS had 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.

Sadly, after almost 20 years since the Ruling, there are ALJs as ignorant of the illness as in 1993.

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. *Mongeluzo v. Baxter Travenol Long Term Disability Benefit Plan*, 1995 WL 34268 (9th Cir. (Cal.)) Important decision upholding CFS claim against employer disability carrier; carrier

claimed that the person with CFS 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.