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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DISCLAIMER

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 many 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.

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 VI

Disability Case Reviews

Once you have been approved for Social Security Disability (SSDI and SSI) and are receiving benefits, Social Security, periodically, will conduct a review of your case in order to re-determine your eligibility for benefits.

The purpose of the review is to determine whether the individual remains totally disabled; that is, the individual is still unable to do any work, even part-time sedentary work on any predictable basis.

If Social Security finds the individual is no longer disabled the benefits will be discontinued.

The new 1999 Social Security Ruling on CFS requires the same specific documentation for reviews as it does for an application. Please review carefully the section of this booklet which explains the Ruling.

During a review, you will have to establish that you have a medically-determinable impairment – CFS. Your doctor will have to document the required medical signs and laboratory tests – or "other findings which are consistent with medically-accepted clinical practice and is consistent with other evidence in the clinical record." Again, the required documentation should include a longitudinal clinical record of at least 12 months prior to the date of the review. Because a review can come at any time, **a Person with CFIDS (PWC) should maintain a continuing relationship with a doctor**, who, at least at 3 to 6 month intervals, should note medical signs in the record and take periodic lab tests. Of course, if a review can be anticipated, the patient should improve the frequency of entries in the clinical record during the 12 months prior to the review.

The doctor's medical report must also document the PWC's inability to work. This documentation should also be noted periodically in the clinical record. Please see other portions of this booklet including "Documenting the PWC's inability to work." Also, as noted in the Ruling in the section, "Letters Supporting the Disability Claim", you should submit appropriate letters from other persons.

When a review begins, you will receive a letter announcing the review. Although the letter may not state that you are required to take any action at this stage of the review, once you receive the letter (if you are still disabled) you should immediately contact your physician(s) **in order to obtain a current medical report/physician's letter.**

(Sometimes, a person will receive a "pre-review questionnaire" containing a few simple questions. This purpose of this form is simply to determine, by the answers to the questions, whether the person should be reviewed. For instance, if the person answers that they are improved, or that their doctor says they can work, then a review may be undertaken. If you receive such a form, answer the questions carefully and make sure they reflect the ongoing severity of your disability. If you have any questions, call the disability committee at 617-522-5835. Also, if you are in any doubt that a review has actually begun, you should call Social Security and ask. If a review has begun, you must act.)

The physician's letter/report should comprehensively document the following:

1. Your continuing diagnosis(as). Your doctor(s) should document, in detail, the chronicity and severity of your major symptoms and should provide a full assessment and prognosis of the continuing severity and chronicity of your disabling illness(as). The doctor should also report on any failure of improvement and treatment since the award of benefits.

2. Your doctor should document how the continuing seriousness of your illness and symptoms totally disable you from working. He/she should also document how your illness severely limits your ability to function in the primary areas of your life: personal care, household duties, family life, social life, etc.

The same general instructions apply for the type of documentation to be included in doctors' letters for reviews as apply for medical reports submitted in the various application stages. Therefore, for more detailed information on the type of documentation and language to be included in review letters, see Appendix II.

You should maintain a continuing relationship with your physician(s) and providers so that you will be in a position to timely document your disability during a review. Urge your doctor to prepare your report as soon as possible. If you can, obtain a copy of the report and submit it to Social Security as quickly as possible. If not, try to make sure your doctor submits the report as soon as possible.

It is of utmost importance that Social Security obtains the letters/reports before the agency makes an initial decision on your review. Often individuals are initially found not to be disabled because the state agency does not receive the medical documentation quickly enough. It is much better to get re-approved immediately rather than having to go through appeal stages -- even though you are likely to be re-approved at a later stage if you can provide the necessary documentation.

If, after the initial review, you are told that you have been found not to be disabled, you should appeal immediately in writing for reconsideration. You may have all your benefits continued until a decision on reconsideration, but only if you specifically request in writing that your benefits be continued and only if you do so within 10 days of the initial rejection decision. (You have 60 days to file for reconsideration, but if you want your benefits continued, you must act within 10 days.)

During reconsideration you may be asked to attend a face-to-face hearing with the person reconsidering your case to explain why you feel you are still disabled and to submit any further documentation of your disability. If you did not provide the necessary documentation at the initial review stage, be sure to obtain and submit the documentation at this time. Although you may be told the reconsideration hearing is informal, it is in fact a serious and legal hearing -- it is possible to make a mistake at this hearing that your attorney will not be able to correct at a later stage. Therefore, individuals are advised not to attend reconsideration hearings without representation by an experienced disability advocate or attorney.

Very often disability benefits will be reinstated at the reconsideration stage. If you are again turned down, you should immediately appeal for a hearing before an administrative law judge. This appeal hearing is similar in nature to the appeal hearing that occurs during the application process. Please see Appendix III for advice on necessary hearing preparation. You should definitely have an experienced

attorney or advocate represent you at the hearing.

If you are turned down at reconsideration after you have been afforded an opportunity for a face-to-face hearing, your benefits will be discontinued. If this happens, you should file an appeal for an Appeal Hearing. If you win, your benefits will be restored. If you requested that your benefits be continued through reconsideration and you do not win after further appeals, you are generally required to repay the benefits you received following the initial rejection. However, you may apply for a waiver so that you will not have to repay. The waiver may be granted if you can convince Social Security that you asked that your benefits be continued in good faith - that you believed that you continued to be disabled. Moreover, Social Security can take ability to pay into account in seeking repayment.

Frequency of reviews:

When you are accepted for disability your certificate of award tells you when you can expect your first review. Generally, how often your case is reviewed depends on likelihood of improvement and severity of your condition. The following are social security guidelines on the timing of reviews:

Improvement expected: If improvement can be predicted when benefits begin, the first review will occur in 6-18 months.

Improvement possible: If medical improvement is not predicted but is possible, review about every 3 years.

Improvement not expected: If medical improvement is not likely, review will happen every 5-7 years.