

ME/CFS ERISA and Individual Disability Income Long Term Disability Insurance Claims

By: Barbara B. Comerford, Esq.*

This paper will focus on documenting disability in ME/CFS long term disability insurance cases (LTD). But first, let me provide a general background of the types of long term disability insurance claims and common features of each.

ERISA LTD PLANS:

ERISA is an acronym for the Employee Retirement Income Security Act of 1974, 29 U.S.C. §1001, *et. seq.* ERISA governs the administration of employee benefit plans and the rights of beneficiaries under those plans.

Certain plans are exempt from ERISA including:

- Federal, state, or local government plans, including plans of certain international organizations.
- Certain church or church association plans.
- Plans maintained solely to comply with state workers' compensation, unemployment compensation or disability insurance laws.
- Plans maintained outside the United States primarily for non-resident aliens.
- Unfunded excess benefit plans - plans maintained solely to provide benefits or contributions in excess of those allowable for tax-qualified plans. ¹

Many corporate and other private employers offer short and long-term disability insurance coverage to eligible employees as part of an ERISA welfare benefit plan. The LTD Plan provides a percentage of pre-disability income in the event the worker becomes disabled. ERISA LTD plans are governed by regulations issued by the U.S. Department of Labor (DOL), Employee Benefits Security Administration. ERISA welfare benefit plans include health, disability, life insurance, etc.,.

For the short-term disability (STD) period, the employer may simply purchase a disability insurance policy to cover employees who become disabled for a limited initial period or they may offer self-funded salary continuation for that period, or sometimes a combination of both. Strictly salary continuation STD is not governed by ERISA.

An employer may also self-fund long term disability insurance benefits offered to employees through a trust or other instrument, but more commonly, employers fully fund the LTD plan by purchasing a disability insurance policy for employees. In those cases, the long-term disability insurer reviews and decides which claims are paid, and then pays the benefit from its own coffers. It is the classic fox in charge of the chicken coop scenario.

Welfare benefit plans ***are not*** vested benefits like pensions and, as such, may be modified and even terminated by an employer. As a result, an employee must carefully review welfare benefit plan provisions as it relates to their entitlement to those benefits. Plan provisions are often available to employees through online employer sponsored portals, summary plan descriptions (SPD), provided to employees, or through the employer's human resources department.

An individual can also obtain long term disability insurance coverage through membership in professional associations at group rates. (e.g-the ABA, AMA, AICPA etc.,) .² These "group" policies are often deemed to be governed by ERISA.

Individuals can also privately purchase disability income (DI) insurance directly through an insurance broker. Those DI policies are not governed by ERISA, but rather state insurance laws. Unlike the limited remedies available to ERISA LTD claimants who are denied benefits, claimants denied benefits under a privately purchased disability policy can seek bad faith and other consequential damages when the LTD insurance company has acted egregiously in denying the claim. There are no bad faith damages available to plaintiffs in an ERISA LTD benefit litigation case.

Theoretically, both ERISA LTD and DI LTD provide long term disability insurance coverage (hereinafter LTD) to ensure financial security in the form of income protection, in the event an individual becomes too disabled to work. At least that is the promise.

The DI policy usually provides a fixed amount of monthly LTD benefits based on income information provided by the claimant in his/her initial insurance application to the broker and the insurance company. Some individuals fail to purchase adequate DI insurance because they do not want to pay higher premiums. Unfortunately, when that occurs, and disability strikes, they find themselves underinsured and unable to meet their living expenses. Anyone contemplating purchasing DI LTD insurance must engage in full disclosure when answering questions on the initial application. Some brokers encourage disability insurance applicants to just check "no" to all questions pertaining to past health problems to ensure their commission on the premium paid by the consumer. But if an applicant fails to answer the questions honestly and fully, the insurer will later demand rescission of the policy, and limit payment to reimbursement of premiums paid, at the very least, or a claim of fraud at worst. Better to disclose any past health issues upfront and know where you stand in the event you become disabled from that condition. If you disclose past conditions in the application, the insurer may either exclude the past illness from coverage under the DI policy, or agree to lift the exclusion after a certain period. Or the insurer may simply assess a higher premium payment to cover the past illness. Again, full disclosure is always important.

Many DI policies do not offset Social Security Disability benefits. But most ERISA LTD insurance benefits are offset by an employee's award of SSD benefits (often including dependent benefits). However, it is important to review the policy provisions under both the ERISA LTD Plan and the DI policy to determine what "other income" benefits are or are not offset. The Courts generally construe the LTD Plan and/or the policy language to control such issues. It is therefore critical to understand the policy provisions prior to filing a claim for disability benefits.

ERISA LTD monthly insurance benefits are usually based on a percentage of an individual's pre-disability income, often between 50-70%. The Plan will generally list the classes of employees and the LTD options provided to each. Some employers pay the entire premium with before-tax dollars, and the LTD benefits are taxed to the employee as ordinary income. Other employers offer group LTD benefits to the employee and the opportunity to pay the premium through payroll deductions using after tax dollars. To determine whether the benefits are taxable, the employee must determine whether the employer or the employee is paying all or part of the premium. And the employee should always consult with a tax advisor about whether and to what extent the benefits are taxable.

The LTD Plan will also define "pre-disability income" and whether bonuses, commissions etc., are included in that calculation or whether it is limited to base income.

"Disability" is defined under the ERISA LTD Plan, and within the DI policy. The definition of disability can vary wildly but most frequently, "disability" requires proof that the claimant cannot perform the material and substantial duties of his/her own occupation, and/or proof that the claimant cannot perform the duties of any occupation.³

Basic considerations for the ME/CFS claimant when filing a long term disability insurance claim

1) Find a ME/CFS medical specialist to provide treatment and not just serve as a consultant.

The most important starting point for anyone suffering from ME/CFS, whether filing a disability claim or not, is to obtain medical care from a physician or other medical provider experienced in treating patients with ME/CFS who understands the myriad symptoms patients experience. If your physician is uninformed about your illness, you will not only not receive proper medical treatment, you may be misdiagnosed and led down a path that will undermine your efforts to address your symptoms and document your disability claim. And as importantly, the LTD insurance carriers do not ordinarily retain medical vendors with expertise in ME/CFS. As a result, your specialist will bring knowledge and expertise in terms of credentials during the claim process, and in any future litigation.

The ME/CFS treating physician will often be the first person to recommend filing for disability when the patient's symptoms are prolonged and severe. A patient must accurately report the symptoms/limitations to the physician to assist in devising a treatment plan and to clinically document the medical chart.

2) Keep a Journal of Daily Complaints and Functional Limitations

ME/CFS patients often complain of brain fog or other cognitive issues which impact memory, among other things. All ME/CFS patients should maintain a daily log of all symptoms and functional limitations and give a copy to the physician during each visit to include within the patient's chart. Patients often feel they are taking up too much of the doctor's time, or they are nervous and forgetful during the visit, or they do not want to appear to be complaining, especially if a recommended treatment has not resulted in improvement of symptoms. As a result, the medical chart often fails to document the actual state of the patient's health, and the functional limitations which result. The symptom/limitation journal can therefore provide a more accurate picture of the patient's symptoms and limitations and, when given to the physician during a visit, becomes part of the chart for a physician to review for treatment purposes, and to answer questions posed by the insurance company.

ME/CFS patients often experience "good days" and "bad days" and contemporaneously chronicling activities on those days is important. For example, if taking a shower on a good day requires the ME/CFS patient to rest after for a period because he is exhausted, that should be written in the journal.

ME/CFS patients often define a "good day" as a day when he/she can perform one or two activities with rest intervals, which is hardly a good day to most people.

On bad days, the level of function can plummet to little more than eating, drinking and going to the bathroom. Even showering is often too taxing for ME/CFS sufferers. And a contemporaneous description of such days is critical in this context, especially when LTD insurance companies often employ surveillance to undermine ME/CFS claims.

For example, if a private investigator retained by the LTD insurer records an ME/CFS claimant driving to the grocery store to buy a few items, then perhaps observes them stopping at the dry cleaner, they may extrapolate from that normal functional abilities that are misleading. If a claimant's journal entry on that day, however, documents symptoms and limitations not visible to the camera (mental exhaustion, and/or physical pain followed by a complete physical crash after the person gets inside his/her home) that journal entry does not merely document the claimant's actual state of health, it also undermines the insurer's attempt to paint the claimant's functional abilities in a false light.

A common tactic of LTD insurers is to schedule a medical exam by one of its medical vendors and then employ surveillance before and after to document the claimant's conduct. In ME/CFS cases, claimants often experience a worsening of symptoms on the day of the

insurance medical exam (Insurers refer to the exams as “independent medical exams” but in my decades of experience in this field, I have seen little evidence of that “independence”).

If an ME/CFS patient experiences worsening of symptoms at any point on the exam day, the claimant, or a family member or friend accompanying them, should document the impact the entire experience had on them before, during and after the visit. The claimant should also share with the insurance medical vendor the effect the experience had on them. (e.g-if they fell asleep in the waiting room, or became dizzy, nauseas, or more symptomatic with pain, fatigue, headaches or cognitive issues etc.) And following the visit, the claimant should describe the entire experience, and the after effect in her journal entry for that day for the treating ME/CFS physician.

The journal will also likely document the unpredictability of the symptoms and limitations from one day to the next, and often from one hour to the next and the frequency of post exertional malaise when activities are performed.

3) An ME/CFS claimant should not participate in standard functional capacity evaluations scheduled by the LTD insurer

LTD insurance companies often try to schedule standard functional capacity evaluations (FCE) (as opposed to a cardio pulmonary exercise test (CPET) performed in ME/CFS cases) to determine whether an ME/CFS claimant has the physical capacity to work. Use of the FCE for that purpose has been discredited for a variety of reasons. ⁴These examiners frequently lack an understanding of the basic issues confronting ME/CFS claimants, especially post-exertional malaise. If an LTD carrier demands the ME/CFS claimant attend a standard FCE, obtain a letter from the ME/CFS treating physician explaining the damage to the claimant’s health. It is a basic tenet of insurance law, that an insured is disabled when the activity in question would aggravate a serious condition affecting the insured’s health. *Lasser v. Reliance Standard Life Ins. Co.*, 344 F.3d 381 (3rd Cir. 2003). The treatise definition of disability holds that “[t]he insured is considered to be permanently and totally disabled when it is impossible to work without hazarding his or her health or risking his or her life,” 31 John Alan Appleman, *Appleman on Insurance* § 187.05[A], at 214 (2d ed.2007). No insurance company has the right to place the life of their insured in jeopardy by requiring that person to return to a position that would raise serious health risks. “Such an approach would force patients with serious health risks to cripple themselves, or even risk death, in order to be considered disabled. . . The law is not so harsh.” *Lasser v. Reliance Standard Life Ins. Co.*, 146 F.Supp.2d 619, 628 (D.N.J. 2001) (Citing *Herring v. Canada Life Assur. Co.*, 207 F.3d 1026 (8th Cir. 2000)).

4) Whenever possible, objectively document the symptoms and functional limitations.

The clinical longitudinal medical record is the first place the long-term disability insurer will look to determine the length of the illness, the signs and symptoms documented in the

record, and what, if any, objective documentation of signs, symptoms and functional limitations exist.

The primary concern of most treating physicians is to document and address patient signs and symptoms, not necessarily to record functional limitations. A hallmark of ME/CFS is debilitating fatigue and post exertional malaise (PEM). The LTD insurer will examine the medical record to determine whether the physician has recorded fatigue and PEM complaints during each visit, if medications were prescribed to address those complaints, the response, positive or negative the patient had to the medications, and any objective testing done to document it. The insurance reviewer will also often ask the treating physician to answer questions about the claimant's functional abilities.

Once again, the patient's journal record of complaints and functional limitations within the chart will give the physician the ability to reply to those questions.

In disability claims, medical documentation of physical exam findings during each visit, as well as, signs and symptoms, treatment plans, and objective test results often control the outcome of the claim. The patient chart charts the course of the claim.

Cardio pulmonary exercise testing (CPET) is a diagnostic test ordered by some ME/CFS specialists to determine the extent of the functional limitations associated with fatigue and PEM. CPET testing is administered over two days when the patient pedals on a stationary bike while resistance is added incrementally. It monitors cardiovascular, respiration and recovery responses, workload, effort and metabolic response/oxygen consumption. The ME/CFS patient performs significantly worse on day two which documents the existence of post exertional malaise. ⁵

While CPET is considered the "gold standard" to objectively document PEM in CFS/ME patients, it must be performed by a provider who understands ME/CFS to avoid misinterpreting the results.

ME/CFS patients often complain of many cognitive deficits including impaired information processing speed, decline in verbal fluency, memory and concentration issues.⁶ The ME/CFS patient should be tested by a neuropsychologist familiar with ME/CFS to ensure the test results are accurately interpreted.

The more objective documentation of the ME/CFS patient complaints, the stronger the case. (with, for example the above tests and tilt table testing⁷ EEGs⁸ QEEGs⁹, SPECT¹⁰ scans, PET¹¹ scans MRIs etc.,)

5) Statements from family members and friends familiar with the ME/CFS claimant's complaints and limitations help

ME/CFS patients are often forced to rely on family and friends for assistance in performing activities of daily living, and care. Statements from family and friends documenting what they see, hear and do for the ME/CFS claimant on a regular basis add to the record in the event an LTD claim is denied.

In ERISA LTD cases, the contents of the administrative record often determine whether the case is later won or lost not merely during the administrative appeal stage, but in litigation. Courts in ERISA LTD cases are often limited to determining whether the insurance claim reviewer abused its discretion in denying the claim. In such cases, the Court may not substitute its opinion for that of the insurance company unless an abuse of that discretion is found. As a result, if the LTD insurer ignores the substantial evidence of record, cherry picks only unfavorable evidence from the record to deny a claim, or otherwise fails to conduct a full and fair review of the claim, it may be found to have abused its discretion. As a result, the medical evidence of record in support of disability, and the ME/CFS claimant documentation of complaints and functional limitations which are also supported by statements of family and friends contribute to the substantial evidence of record in support of the claim.

6) Provide a “before and after” record of function

Occupational demands: Disability insurers require all claimants to describe their work history, especially the occupational demands prior to disability onset. Production of a resume is insufficient to document work demands. ME/CFS claimants are often debilitated by fatigue and suffer impaired cognition so this request is often daunting for them. As a result, ME/CFS claimants should obtain a job description from the employer whenever possible. The claimant can then supplement that job description when responding to the LTD occupational demand questions. ME/CFS claimants whose jobs required superior cognitive skills, should also emphasize that in response to these questions. Along those lines, if travel or attending meetings was required, or where quickly processing complex (or any) information and discussing it with others, or multi-tasking and working under constant deadlines were part of the occupational demands, all of that must be noted and why ME/CFS symptoms prevent the claimant from performing those demands.

Any employer evaluations of the claimant/employee conducted in the years prior to disability and following disability onset are important to include in the administrative record. Any bonuses given to the ME/CFS claimant pre-disability which were performance related should also be noted. Often ME/CFS patients go from being top performers at work to crashing over time. Documentation of that work performance decline and employer comments about it provide critical independent documentation to add to the administrative record.

If an ME/CFS claimant was physically active and engaged prior to disability, but has abandoned all or many of those activities, that should also be documented.

Conclusion

The ME/CFS claimant must document the total adverse effect the constellation of these symptoms has on his/her life. The claim must provide medical support and documentation of symptoms and limitations (physical and cognitive) by experienced ME/CFS medical providers. The ME/CFS claimant should contemporaneously journal daily complaints and functional limitations and provide that journal to the ME/CFS providers during each visit. Objective

documentation of complaints and functional limitations is crucial in ME/CFS disability claims. Statements from family and friends who are familiar with the claimant's complaints and limitations provide additional evidence in support of disability. And documentation from the employer about the occupational demands, and the ME/CFS claimant's decline in the form of performance evaluations, etc., are important evidence to include within the administrative record.

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¹ *Id. In Pilot Life Insurance Co. v. Dedeaux*, 481 U.S. 41 (1987) the Court held that Mississippi's common law bad faith remedy 'related to' an ERISA plan, and therefore fell within the scope of preemption. The Court also found that the bad faith law was not saved from preemption as a law that regulates insurance because, in Mississippi, the bad faith remedy is available for any aggravated breach of contract, not just the breach of insurance contract. The Court applied a three factor test developed under cases interpreting the phrase 'business of insurance' in the McCarran-Ferguson Act to define which state laws regulate insurance and explained that a state law 'regulates the business of insurance' when the law affects the spreading of a policyholder risk, affects an integral part of the insurer/insured policy relationship and specifically targets the insurance industry. The Court concluded that while the law affected the insurance industry, it did not specifically target it or affect an integral part of it, and did not spread policyholder risk. Therefore no bad faith damages were permitted. However, in 1999, in *Unum Life Insurance Co. v. Ward*, 526 US 358 (1999) in an ERISA LTD case in which Unum had argued that the plaintiff had waited too long under the relevant policy provisions to file a timely claim for disability benefits, Justice Ginsburg, writing the unanimous opinion for the Court, noted that the "parties agreed that the notice-prejudice rule fell under the ERISA preemption clause, § 514(a) as a state law that 'relates to' an employee benefit plan. Their dispute hinges on the question: Does the rule 'regulate insurance' and thus escape preemption?" She then worked through the McCarran-Ferguson criteria agreed with the Ninth Circuit Court of Appeals opinion in the matter that the notice prejudice rule "appears to satisfy the common sense view as a regulation that hones in on the insurance industry and does "not just have an impact on {that} industry. In doing so, the Court rejected UNUM's contention that "bracketing California's notice prejudice rule for insurance contracts with Mississippi's broad gauged 'bad faith' claim for relief." But a later U.S. Supreme Court case discarded the McCarran-Ferguson factors in the context of an ERISA HMO case. In *Kentucky Association of Health Plans, Inc. et*

al v. Janie A. Miller, Commissioner, Kentucky Department of Insurance, 123 S. Ct. 1471, 155 L. Ed. 2d 468, 2003 U.S. LEXIS 2710 (2003) Justice Scalia, writing for a unanimous Court, ruled that for a state law to be deemed a law which regulates insurance under 29 U.S.C.S. § 1144 (b)(2)(A) (and avoid ERISA preemption) it must satisfy two requirements: 1) the state law must be specifically directed toward entities engaged in insurance and 2) the state law must substantially affect the risk pooling arrangement between the insurer and the insured. Justice Scalia noted, “Our holding in UNUM...that a state law may fail the first McCarran-Ferguson factor yet still be saved from pre-emption under § 1144 (b)(2)(A) raises more questions that they answer and provides wide opportunities for divergent outcomes...Today we make a clean break from McCarran-Ferguson factors...”

² Advisory Opinion Letter of Robert J. Doyle, Director of Regulations and Interpretations, U.S. DOL, PWBA Office of Regulations and Interpretations, dated July 11, 1994 re: 94-25A ERISA Section 3(1), 2510.3-1(j)

Section 3(4) of Title I of ERISA provides:

(4) The term "employee organization" means any labor union or any organization of any kind, or any agency or employee representation committee, association, group, or plan, in which employees participate and which exists for the purpose, in whole or in part, of dealing with employers concerning an employee benefit plan, or other matters incidental to employment relationships; or any employees' beneficiary association organized for the purpose in whole or in part, of establishing such a plan.

Section 3(1) of Title I of ERISA defines the term "employee welfare benefit plan" to include:

[A]ny plan, fund, or program which was heretofore and hereafter established or maintained by an employer or by an employee organization, or by both, to the extent that such plan, fund, or program was established or is maintained for the purpose of providing for its participants or their beneficiaries, through the purchase of insurance or otherwise, (A) medical, surgical, or hospital care or benefits, or benefits in the event of sickness, accident, disability, death or unemployment, or vacation benefits, apprenticeship or other training programs, or day care centers, scholarship funds, or prepaid legal services, or (B) any benefit described in section 302(c) of the Labor Management Relations Act, 1947 [29 USCS section 186(c)] (other than pensions on retirement or death, and insurance to provide such pensions).

29 C.F.R. section 2510.3-1(j). Regulation section 2510.3-1(j) describes certain group or group-type insurance programs in which the involvement of the employer or employee organization in the operations of the program is so minimal that such involvement does not constitute establishment or maintenance of the arrangement for purposes of ERISA section 3(1).

Section 2510.3-1(j) provides:

(j) Certain group or group-type insurance programs.

For purposes of Title I of the Act and this chapter, the terms "employee welfare benefit plan" and "welfare plan" shall not include a group or group-type insurance program offered by an insurer to employees or members of an employee organization, under which

(1) no contributions are made by an employer or employee organization;

(2) participation in the program is completely voluntary;

(3) the sole functions of the employer or employee organization with respect to the program are, without endorsing the program, to permit the insurer to publicize the program to employees or members, to collect premiums through payroll deductions or dues checkoffs and to remit them to the insurer; and

(4) the employer or employee organization receives no consideration in the form of cash or otherwise in connection with the program, other than reasonable compensation, excluding any profit, for administrative services actually rendered in connection with payroll deductions or dues checkoffs.

A program will be excluded from Title I of ERISA pursuant to regulation section 2510.3-1(j) only if the activities of the employer or employee organization do not exceed any of the limitations set forth in the regulation....And see Department of Labor Opinion Letter to Mr. Jerry L. Oppenheimer, dated Dec. 16, 1976, In that letter the Department opined that a communication to employees or members that states that the employer or employee organization is "enthusiastic" about a program would be an endorsement within the meaning of section 2510.3-1(j)(3). Similarly, a communication that states that the employer or employee organization has "arranged" for a group or group-type insurance program might be an endorsement if, taken together with other employer or employee organization activities, it leads employees or members to reasonably conclude that the insurance program is one established or maintained by the employer or employee organization.

³ Variations of the definition of disability are common and therefore the policy must be carefully reviewed to ensure that the claimant satisfies the definition and the proof of claim requirements contained within the policy itself. For example, some LTD policies only require proof that the claimant cannot perform the duties of his own occupation for the duration of the policy period of coverage; other policies might contain a requirement that the claimant prove he cannot perform the duties of his own occupation for a limited period (eg 24 months) followed by proof that the claimant cannot perform the duties of any occupation for the balance of the policy period. (commonly to age 65 or full retirement age).

⁴ http://www.fmnetnews.com/wp_content/uploads/disabilityfibroversionjuly2207.pdf a
<https://www.prohealth.com/library/the-functional-capacity-evaluation-fce-and-your-disability-insurance-benefits-33900>

⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482824/> and
<http://neuroimmune.cornell.edu/research/physiology/>

<https://www.ncbi.nlm.nih.gov/m/pubmed/23527651>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4734796/> Forty-seven outpatients were selected over a 3-month period and divided into an observation group (24 outpatients) and a control group (23 outpatients) by using the

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Results

1) BEAM results indicated that the energy values of δ , θ , and α_1 waves significantly increased in the observation group, compared with the control group ($P < 0.05$, $P < 0.01$, respectively), which suggests that the brain electrical activities in CFS patients were significantly reduced and stayed in an inhibitory state; 2) the increase of δ , θ , and α_1 energy values in the right frontal and left occipital regions was more significant than other encephalic regions in CFS patients, indicating the region-specific encephalic distribution; 3) the correlation dimension in the observation group was significantly lower than the control group, suggesting decreased EEG complexity in CFS patients. The spontaneous brain electrical activities in CFS patients were significantly reduced. The abnormal changes in the cerebral functions were localized at the right frontal and left occipital regions in CFS patients.

^{6 6} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482824/> and <http://neuroimmune.cornell.edu/research/physiology/>

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⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482824/>

⁹ <https://sciforschenonline.org/journals/clinical-research/CLROA-2-110.php>

¹⁰ <http://www.ncf-net.org/library/sp.htm> Patients with AIDS dementia complex had the largest number of defects (9.15 per patient) and healthy patients had the fewest defects (1.66 per patient). Patients with chronic fatigue syndrome and depression had similar numbers of defects per patient (6.53 and 6.43, respectively). In all groups, defects were located predominantly in the frontal and temporal lobes. The midcerebral uptake index was found to be significantly lower ($p < .002$) in the patients with chronic fatigue syndrome (.667) and patients with AIDS dementia complex (.650) than in patients with major depression (.731) or healthy control subjects (.716). Also, a significant negative correlation was found between the number of defects and midcerebral uptake index in patients with chronic fatigue syndrome and AIDS dementia complex, but not in depressed patients or control subjects.

¹¹ <https://prevention.nih.gov/docs/programs/mecfs/ODP-P2P-MECFS-FinalReport.pdf>