

Barbara Comerford, ESQ, was one of the speakers at the New Jersey CFIDS Association conference held on October 17, 2010. Previously, she has held a post as a board member of the NJ CFIDS Association, The CFIDS Association of America (CAA), The American Association of Chronic Fatigue Syndrome (AACFS) before it became the International Association of Chronic Fatigue Syndrome (IACFS), and helped work on the physician's manual that the NJ CFIDS Association published. She has a practice specializing in disability law in the jurisdiction of New York and New Jersey. Through her work, Ms. Comerford has become a specialist in CFIDS disability and spoke to the issues CFIDS patients need to know.

Although many patient organizations and some physicians refer to this illness as CFIDS, the government's official name is still Chronic Fatigue Syndrome (CFS) and that is the name Social Security Administration (SSA) uses. Ms. Comerford concentrated her speech on the high points regarding Social Security Disability Insurance (SSDI) and Long-Term Disability (LTD).

## **Social Security Disability Process**

Ms. Comerford gave some background on why the [SSA ruling SSR 99-2p](http://www.socialsecurity.gov/OP_Home/rulings/di/01/SSR99-02-di-01.html) ([http://www.socialsecurity.gov/OP\\_Home/rulings/di/01/SSR99-02-di-01.html](http://www.socialsecurity.gov/OP_Home/rulings/di/01/SSR99-02-di-01.html)) was issued on April 10, 1999. According to the SSA, the purpose of the ruling was to “restate and clarify the policies of the Social Security Administration for developing and evaluating title II and title XVI claims for disability on the basis of Chronic Fatigue Syndrome (CFS), also frequently known as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS).”

She explained that the CAA had requested guidelines from the SSA for adjudicating CFS cases when it was learned that an Administrative Law Judge (ALJ) had written a memorandum to the chief ALJ basically stating that the CFS cases could never win because there was no objective medical basis for the diagnosis.

At the time, the SSA Commissioner, Susan Daniels, wrote a response basically saying just because the science has not caught up with the illness does not mean these people are not disabled and that the SSA needs to look at these cases slightly differently. SSR 99-2p is the guideline the SSA created for evaluating CFS cases. Every disability case is reviewed according to a 5-step process regardless of illness type. Ms. Comerford has written many articles on this process. To learn more, go to her website at [www.tristatedisabilitylaw.com](http://www.tristatedisabilitylaw.com) where her articles are posted.

The five things evaluated for every claimant under the Sequential Evaluation Process require:

1. That you not be engaged in substantial gainful activity;
2. That the medical impairment be documented with medical signs and lab findings;
3. That it be determined if an applicant's illness meets or equals an “Impairment Listing”; Ms

Comerford explained that this listing has 14 bodily systems and CFS is not among any of them, causing CFS cases to be evaluated in subsequent steps;

4. That you cannot perform your past work;
5. That the SSA has to prove there are no jobs that the claimant can do at any level, in light of his or her age, education, work experience and the limitations imposed by CFS.

Ms. Comerford explained why the SSA looks at the above list and what they are looking at with regards to CFS patients. Under SSR 99-2p, the SSA is looking at:

- Can the patient satisfy the Fukuda Definition of CFS that the Centers for Disease Control & Prevention (CDC) uses?
- Does the patient have medical evidence in lab work that something is wrong? Some but not all examples are: autonomic dysfunction; postural tachycardia; neuropsychological testing which can show the slowed cognitive function or slowed processing of the brain; a positive tilt table test; Epstein Barr Virus (EBV) activation; Human Herpes Virus 6 (HHV6) activation, Fibromyalgia tender point exam.
- Is there clinical longitudinal documentation by the physician that shows there is an impairment in functioning? This is CRUCIAL and the problem is most doctors DO NOT keep these types of records.

She also pointed out that there are two things that are important for the patient to have:

- a physician willing to do the NECESSARY paperwork required for SSDI (most won't);
- a physician who BELIEVES in the patient and the illness and is willing to fight for the patient.

Ms. Comerford said that as expensive as it is, and most likely not covered by insurance, neuropsychological testing is one of the best ways to show slow brain processing and the cognitive impairment associated with CFS before an Administrative Law Judge (ALJ).

It is important for the patient to have a good lawyer who not only understands this illness but who is also able to frame the case in a manner the ALJ can understand. For instance, the lawyer may be able to make the case that decreased brain and cognitive function can impact the claimant's ability on the job. This then would help document a disability. Or a patient who has Orthostatic Hypotension and can't sit or stand up for more than a few minutes at a time would also be considered as having a disability.

## **Private Long Term Disability Insurance process**

Ms. Comerford then explained the process that occurs when a patient files for Long Term Disability by virtue of his or her employment. This is a much more difficult standard if the plan

under which these claims are paid lets the fiduciaries (the companies) who make the decision on a claim do so “in their discretion.” She stated that this language “in their discretion” is almost always in a company’s contract and what it means is that the decision of disability is up to the insurance companies. And, in many cases they will turn you down. If the case goes to court, and many do, the insurance company’s lawyer can present pictures of the disabled patient out mowing the lawn, carrying groceries etc. because the insurance investigators are out there, and are known, at times, to investigate people using a variety of methods, including long lens cameras, talking to neighbors, etc. Ms. Comerford knows that on a good day, patients have a tendency to do all that is possible because they do not know when another good day will come around. Insurance companies fighting disability use every trick they legally can. Having a disability lawyer who does not understand how this illness works and how to fight the insurance companies is very challenging for the patient. Having a lawyer who can explain the illness and the unsustainability of it goes a long way.

Ms. Comerford also said conflict of interest still matters to the courts. In some cases where an insurance company under ERISA both pays the proceeds (i.e. benefits) and determines eligibility for benefits there can be an inherent conflict of interest. Then the patient’s lawyer must show the court that the process in which the case was evaluated was very, very faulty to the point of abuse of “their [the insurance company’s] discretion.” One way that this can be shown is to present enough medical documentation along with strong evidence that those medical findings limit the patient’s ability to function.

Then, the court also evaluates whether the insurance company based its decision on their nurse’s paper review; the opinion of their (the insurance company’s) doctor who has no CFS background; as opposed to the recommendations and opinions by a physician who knows this illness. The courts will consider this issue because CFS and FM require a tremendous amount of specialization.

Another situation the court will look at is if the insurance company is not paying any attention to a favorable SSA ruling for the patient. Most insurance companies require the patient to file for SSDI because their financial exposure is less if they are paying the claim. Once the person gets awarded SSDI, the insurance company may claim any “overpayment” they have made that overlaps with retroactive Social Security benefits. If the patient ever has to go to Court to appeal an LTD rejection, his or her lawyer could argue that the federal government – the Social Security Administration – has determined the individual is disabled. Courts will also look at whether the insurance company took into account the unpredictability of this illness, which Ms. Comerford stated as one of the worst and most disabling symptoms of this disease, as well as the unsustainability of activity and post exertional malaise. The unpredictability and unsustainability are hallmarks of this illness, and as she said “What employer wants an employee that cannot predict that they can show up for work from one day to the next?” If the insurance company ignores the unsustainability and has a video showing a patient lifting a twenty-pound bag, chances are tomorrow the patient will be in bed all day. It is that unsustainability that is important for the court to understand.

## **What the patient can do**

Ms. Comerford stressed that it was a good idea for the patient to keep a daily log of the medications he or she takes and the activities he or she engages in. It may well be the best documentation the patient has. It could show that upon short activities, such as taking a shower, the patient has to get back into bed for an hour or so to recover from that activity. Unfortunately, it is not uncommon for a patient to be unable to keep such logs because it becomes just one more thing that “has to be done.” However, it is an important thing to do. As good as a patient may physically look, the log shows the instability of functionality for the patient.

The biggest take away from this speaker was the unsustainability of activity for CFS patients and how that helps with attaining disability. If the patient and doctor can show (through doctor’s notes or patient logs) that the patient can not sustain normal activity, and has some medical testing showing abnormalities, it helps the CFS patient gain disability. Ms. Comerford closed by saying that it all begins and ends with the medical documentation.

## More Resources

For further detailed information, see Ms. Comerford's article [PROVING THE CFS DISABILITY CASE](#), posted on the NJ CFIDS Association website. <http://www.njcfsa.org/DisaComf.html>

For a detailed information of all aspects of disability as it relates to CFIDS and FM, including our Disability Handbook, please see our section on [Disability](#) .

[Ms. Comerford's website](#) has many other articles on disability law topics.