

AFFIDAVIT OF [REDACTED]

I, [REDACTED], being first duly sworn upon oath, depose and state that I am over eighteen (18) years of age, have personal knowledge of and am competent to testify to the following:

AUTHORSHIP OF THIS DOCUMENT

This affidavit was compiled over a period of several months with input from myself and extensive writing support from several people, primarily my sister, [REDACTED], and my attorney [REDACTED], Esq.

LTD CASE AND TERMINATION SYNOPSIS

My name is [REDACTED] and I am the claimant in the [EMPLOYER] Long Term Disability (LTD) case # [REDACTED] which has been terminated after a cursory review by Sedgwick CMS, the new administrator under contract to [EMPLOYER]. [Initial TPA] administrated my Short Term Disability (STD) case from May, 2003 to May, 2004 and my LTD case from May, 2004 to December 2006. [REDACTED]

Under [Initial TPA], my claim had undergone extensive regular reviews. Twice I was placed under surveillance and they had me twice participate in very comprehensive Independent Medical Evaluations (IME), one lasting over a two day period. According to the case file, the reviews were thorough with multiple internal consulting physicians concurring with the IME specialists regarding my inability to return to work.

Shortly after assuming management of my case, Sedgwick undertook a cursory review of my claim. In May 2007, without either ordering an IME, consulting me or my treating physician regarding what they perceived as ‘inconsistencies’, or even reviewing the extensive [Initial TPA] content in my file, Sedgwick terminated my LTD. The Sedgwick termination process basically involved requesting ten months of records from my Primary Care Physician (PCP), placing me under surveillance for three days, and a “discovery” of very limited volunteer work that I have been performing for a local youth recreational league. Based on this very cursory review and analysis, Sedgwick promptly terminated my benefits.

The case file shows that the Sedgwick Case Manager did not review, because she did not even have in her possession, the extensive record that included extensive Objective Medical Evidence supporting my claim. This is the information that was compiled by the previous claims administrator, [Initial TPA]. When my attorney requested my complete case file (for the second time, as the first time the [Initial TPA] period information was not included in any legible format the first request), it was revealed that they had to request it from [Initial TPA] so they could send it to us. Sedgwick continued to omit information from my case file and even the third request did not include complete information from my case, including critical internal medical

reviews. This process has taken over three and a half months, well beyond the thirty day ERISA requirements.

The ten months worth of notes from Dr. [REDACTED], my primary care physician (PCP), Sedgwick reviewed were basically routine office visit notes as he attempted various therapies. The bulk of my extensive Objective Medical Evidence was prior to this time, was ignored by the case manager and not provided to the “Physician Advisor” under contract to Sedgwick. Furthermore, the case file shows that this “Physician Advisor” spent no more than a few hours on the assessment and documentation of this very complex case. Yet he stated, without requesting any additional information or scheduling an IME, that there was no ‘current’ objective medical evidence to support my ‘alleged symptoms’.

Regarding the surveillance Sedgwick had me under for three days, two of the days I was observed leaving the house once each day for very brief periods (the first in my bathrobe retrieving my cat from a neighbor’s yard, the second driving my daughter one mile to school). On the middle day, I was observed driving my son 57 miles to a baseball event. Sedgwick has turned this into my ability to ‘drive extensive distances’ and stating that it is “inconsistent” with my “alleged” complaints. They also stated that I showed no limitations. This is in fact not inconsistent with my complaints, especially in context of the diagnosis I have received, and there were in fact several limitations during this drive. This will be fully explained later in this statement. These were limitations that an investigator is in no way capable of recognizing, nor did he attempt to. Furthermore, per the case file, the case manager did not even review the video of me when translating the investigator’s notes of my activities into her subjective and invalid conclusions. We know this because when my attorney requested the video, the case file shows that the case manager at that point had to request it from the Investigative firm as it had not been previously sent to her. When we did receive the video, it was of such poor quality it was hard to make out much detail at all.

Perhaps the most outrageous example of Sedgwick’s handling of the case is in regards to my community volunteer activities. While I appreciate the case manager’s diligence in researching any activities I am involved in and I fully understand the nature of this business and the fraud that occurs by people faking disability, one trusts that the insurance company will take their responsibility seriously and act in a fair and objective manner in order to determine the truth behind any disability claim. I have always provided full disclosure when dealing with everything involved in my claim, and have been open and honest regarding all outside activities. On my initial application for LTD in 2004 I described the volunteer activity. I discussed and cleared it with both my treating physicians and the IME doctors [EMPLOYER] arranged for me, all of whom encouraged the activities helpful to my illness. This activity not only required minimal time (5-10 hours/7 day week) on a very flexible basis, but also provided a great therapeutic value as well. My physicians recommended it as long as I kept within the bounds of my illness as it provided some physical and mental stimulation, which helps prevent both physical and cognitive atrophy and helps prevent depression in chronically ill patients. Unfortunately the case manager saw fit to simply find that I had a lofty title of “Director of Referees”, discovered a ‘sample’, ‘typical’, or ‘common’ (depending upon who she was communicating with) description of this role from a much larger organization and had been given a volunteer award by the league. Not once did she

contact me or anyone from the recreation league, to find out more information and exactly what this volunteer role entailed. I will describe this further in my statement.

Sedgwick did not undertake a 'careful and thorough' review of extensive file, but rather handled this case in a careless, superficial, and irresponsible manner.

PERSONAL SYNOPSIS

Prior to my going on disability in May 2003, I was a [REDACTED] with [EMPLOYER], having various titles including ' [REDACTED] and ' [REDACTED]. Titles varied based on the assignments and the requirements of the [REDACTED] Executive I was reporting to at any given time.

[REDACTED] Prior to the last six months or so, due to budgeting constraints, this job entailed extensive travel.

Prior to [EMPLOYER] I held a variety of increasingly responsible positions, primarily in the software development arena. At times I managed organizations as large as fifty people. I have always been very high energy and a hard worker. Prior to my illness, my work day typically started between 6:30AM and 7:30AM and often went late into the evening.

I grew up on a farm outside of [REDACTED]. During the weekends and summers I would be busy with everything from raising and showing cattle to painting fences and barn roofs and baling hay. I developed a strong work ethic early and worked throughout college, taking quarters off to work at [REDACTED] as a systems analyst as part of an internship program. I graduated from [REDACTED] in 1982 with a degree which was a combination of Computer Science, Accounting, and Math.

I am currently married but separated and temporarily residing with family members in [REDACTED]. I have two children, currently 16 & 17 years old, meaning they were both entering adolescence and their challenging teen aged years just as I went on disability. My son is currently with his mother and my daughter is residing with me.

In addition to helping out my son's basketball league as I am able, I also volunteer sporadically as parental assistance is required with school activities and even help them out with homework on occasion. I have a strong need to participate in activities, but am only able to on a limited and unpredictable basis due to my illness. In addition to continuing to have to fill the role as a parent regardless of my condition, I had been advised by my physician, Dr. [REDACTED], as well as the Neuropsychologists [EMPLOYER] sent me to for IMEs, that these activities are therapeutic for my chronic condition. I participate as the condition of my illness from day to day allows, unfortunately it is unpredictable and I always make it clear that I can not be relied upon but will help out as I can.

ILLNESS ONSET AND BACKGROUND

Sometime in early 2001, I don't quite recall exactly when, I began feeling fatigued and experiencing cognitive problems. While there were other symptoms, these were the primary issues I became concerned about. I have a reasonably high tolerance for discomfort so most of these other symptoms did not bother me to the point of affecting my performance, either at work or at home at that point

My Primary Care Physician (PCP) at the time, Dr. [REDACTED], began running tests and attempting various therapies in an effort to overcome the problems. I continued to work at my normal pace, including extensive travel, throughout this diagnostic process. Extensive blood testing was performed and various treatments provided, including B-12 shots, hormone shots, antidepressants, and several other things I do not recall.

Once all remedies available to Dr. [REDACTED] were exhausted to no avail, I began seeing all relevant specialists as Dr. [REDACTED] saw appropriate. This included (in no particular order) a Pulmonologist, Endocrinologist, Neurologist, Rheumatologist, Cardiologist and several others. These further evaluations discovered sleep apnea and a Pituitary Tumor. The sleep apnea was treated with a Bi-Pap but the fatigue and cognitive issues were not relieved. I previously had sleep apnea in 1998 and underwent a UPPP, which was successful. The fatigue I was experiencing at this point was much different from the fatigue I suffered in 1998, primarily because of the other accompanying symptoms, most notably cognitive issues. Additional sleep testing (MSLT), while currently under Bi-Pap treatment, by the same Neurologist ruled out Narcolepsy but did diagnose Hypersomnia (Excessive Daytime Sleepiness). I suspect that the multiple antidepressants Dr. [REDACTED] was experimenting with caused weight gain which in turn resulted in excess tissue in my throat causing the Sleep Apnea to reemerge. The fatigue and cognitive issues began long before the snoring from the apnea appeared. The Pituitary tumor was benign and not treatable, although apparently permanent damage had already been done to a portion of the Pituitary Gland.

In the spring of 2003 I began what appeared to be a promising treatment with Provigil. Unfortunately what positive impact it did have wore off after about four weeks of treatment, despite attempting various dosages. In early May 2003 my condition got to the point that I just simply could no longer go into work. For the previous approximately eighteen months I had forced myself to deal with the fatigue and cognitive problems, to the point that I was taking naps at work when I could find a place, sometimes going out to a car or finding an empty conference room. I simply could not deal with it any longer. I began to see Dr. [REDACTED] who fully reviewed all my extensive medical activity, fully evaluated me, and after reviewing the Neurocognitive Evaluation by Dr. [REDACTED], diagnosed me with Chronic Fatigue Syndrome (CFS). Further testing, including a positive tilt table and Functional Capacity Evaluation confirmed his diagnosis and added Neurally Mediated Hypotension (NMH) as a diagnosis, noting low blood volume.

Throughout this illness I have always followed my physician's advice and have aggressively attempted to find treatment that would help alleviate my symptoms to the point that I would be able to return to an employable condition. I have regularly worked with Dr. [REDACTED] and we have actively pursued a number of treatment strategies, including

mega-doses of B-12, Aricept, additional anti-depressant protocols, prolonged and aggressive antibiotic Lyme treatment, and many more that I do not recall. While one or two treatments have had some mildly noticeable and temporary palliative impact, they have had with no significant impact. Additionally, I have participated in CFS related studies funded by the CDC and NIH. For example, I once made several trips to Temple University to participate in a research project evaluating the effects of Creatinine on persons with CFS.¹

I have always cooperated with the requests of the [EMPLOYER], providing all information requested (or that I was aware had been requested) in a timely manner, going to all IMEs they have scheduled and given each and every test my full cooperation and 100% effort (*as is evidenced by statements to that effect in their reports*).

In summation, prior to going on disability I went through almost 18 months of testing and attempting to find what was wrong with me. This was not a sudden issue that I quickly gave up on. I attempted every possible avenue for evaluation and treatment before finally being unable to continue my work.

Any extracurricular activities I currently engage myself in are minimal and only as my body and mind are able at any given time. I no longer am able to enjoy any sports as I did prior to my illness, particularly golf and tennis.

IMPACT OF ILLNESS ON MY FAMILY

The cost of this illness has been substantial, not only in financial terms, but emotional terms as well. Financially, the loss of income has been \$█,000 to \$█,000. I was earning approximately \$█,000 + bonus before my illness struck. Some years I earned almost \$█,000. Additionally, I have been forced to liquidate several investment instruments that had long term financial potential.

Emotionally my children have had difficulty adjusting to a father that is only able to do a fraction of the activities he used to be able to. I used to go to baseball games often with my son; I have been to one since my illness and it was a very difficult experience. We also used to play golf and tennis, neither of which I have been able to do since my illness. I do attempt from time to time to assist my daughter with her tennis, but only to hit to her some simple balls for her to return, and then only from a stationary position and if I am up to it – I never last very long.

I really enjoyed my work; I was working on challenging and creative business partnerships between market leaders leveraging state of the art technology. I traveled extensively and had the opportunity to work with many very talented and interesting people. It is what I had been driving my career towards and found it very fulfilling. I certainly didn't spend all that education and career development to find myself spending most of my time in my bed and around the house all day.

Perhaps the biggest toll this illness has had is on my wife, who became very anxious and terrified about the loss of income and life in general. Since the onset of my

¹ As you have no knowledge my method of transportation, please refrain from making inferences regarding my ability to travel as I assure you they are not supportable.

disability Mrs. [REDACTED]

[REDACTED] Numerous problems have occurred because of this and as a result we have separated as of April of this year.

Shortly prior to my LTD termination by Sedgwick, my wife and I separated and I was in the process of looking for another location to reside in the [REDACTED] area so I could continue to be near my children. However, given the loss of the disability income, I was forced to move in with family members in [REDACTED], dislocating my daughter from her high school and creating excessive angst for both her and my son. The cost to appeal this case will be well in excess \$10,000 at a time when the majority of my income has been cut off. If this statement has made itself to a judge, one can assume that it is by now many times that amount. I am fortunate to have family with the resources to assist me in this process of reinstatement, but this irresponsible handling of my legitimate claim has wreaked havoc on the lives of me, my children, and the rest of my family.

DIAGNOSIS SYNOPSIS

I have two primary diagnoses and several secondary diagnoses. The nature of these is not fully understood in terms of either cause or treatment and there is no known cure. The most relevant diagnoses are Chronic Fatigue Syndrome, Neurally Mediated Hypotension, and Hypersomnia (Excessive Daytime Sleepiness). There are numerous symptoms of varying difficulty for me, but the debilitating conditions from these diagnoses are excessive fatigue and cognitive difficulties. My treating physicians have tried many treatments in an attempt to overcome these issues. Unfortunately, while from time to time there has been some improvement, they have neither been significant or more than temporary.

To understand the combination of debilitating conditions that constitute the disability in my case, it is important to understand the underlying diagnoses. These diagnoses have been made by experts in the relevant field, supported by extensive evidence, objective and subjective, and have concurrence by several medical professionals, including those arranged and paid for on behalf of [EMPLOYER].

CHRONIC FATIGUE SYNDROME (CFS)

When I first heard of CFS, I believe sometime in the late 80's, my reaction was very typical, especially of high energy people; I simply didn't believe it was a legitimate illness. Unfortunately the Center for Disease Control chose to name this complex disorder of the neurological, endocrinological, and immunological systems after the primary symptom that all people having it experience – Fatigue.

The fact is that my CFS was diagnosed by a physician that specializes in CFS by carefully evaluating all relevant information, subjective and objective. Since that time he has been seeing me for over four years and the information

from that care and additional objective medical evidence has continued to validate his diagnosis. Recently I was seen by a nationally recognized expert in CFS who confirmed both the diagnosis and rated my functioning in the “Unable to Work” range on the oft used standard Karnofsky Performance Scale (see Exhibit 3A of Appeal Letter).

NEURALLY MEDIATED HYPOTENSION (NMH)/DYSAUTONOMIA

As I understand it, the physiological manifestation of this in my body is that my systems are severely out of kilter, most notably my brain/heart communication. While there are a number of symptoms, ranging from blurry vision to sudden onset of chills and overheating of my body (I gather my internal ‘thermostat’ is out of whack). Most notably, the Neurally Mediated Hypotension (NMH) is responsible for miscommunication between my brain and my heart and causes a great deal of poor regulation in my blood pressure.

Concurrent with this I have been identified as having ‘low blood volume’ (Dx. Dr. [REDACTED], Oct 2003), which means I have less blood in me than I am supposed to have. In fact, nurses have given up attempting to get blood or give me an IV in my arm, the only place they can locate a vein is in the back of my hand. The last time I gave blood I fainted after giving less than a half a pint.

Additionally, my blood pressure is labile (Dx during FCE at National Rehabilitation Hospital Jan 2004), meaning it jumps around with no rhyme or reason. We have been attempting to normalize this as much as possible with medication and supplements, but the effects of these are as unpredictable as the problem and there is no known cure.

The consequences of all this are actually quite extensive and more than just vertigo and syncope from time to time. To begin with, ninety percent of the time that I am doing something ‘sedentary’ which requires cognitive attention, I do so lying down with my feet propped up. This generally keeps my blood pressure from being too erratic as a result of my blood being relatively evenly distributed. While medical research is not completely clear on this, it seems that between not having enough blood in my system and the flow of that blood being somewhat erratic, it is not effectively being circulated around my body, including both my muscles and my brain, meaning they are not getting sufficient oxygen. In his “*Circulating Blood Volume in Chronic Fatigue Syndrome*”, Dr. David Bell notes “*A subnormal RBC mass and/or decreased circulating blood volume may well result in diminished cerebral blood flow with subnormal oxygen-carrying capacity.*” (Exhibit 22 of Appeal Letter) In July 2007 (post LTD termination) I underwent a CardioPulmonary Exercise Stress Test which showed my ‘oxygen utilization’ at 16.7% (51% of what should be expected). (Exhibit 3B of Appeal Letter) Clearly my body is not processing oxygen the way it should. Is that the cause behind all this fatigue and cognitive dysfunction? We don’t know. Medical research is still working on that. However, it is real and quantifiable on an objective basis, and it IS affecting my ability to function on a consistent and reliable basis.

It seems to me that this would explain both the cognitive and physical fatigue I constantly experience, albeit in varying, and unpredictable, degrees over time.

HYPERSOMNIA (EXCESSIVE DAYTIME SLEEPINESS)

Diagnosed during a Multiple Sleep Latency Test (MSLT) (Dr. [REDACTED], August 2003). During this study they also ruled out narcolepsy. The National Institutes of Health (NIH) describes Hypersomnia as “*characterized by recurrent episodes of excessive daytime sleepiness or prolonged nighttime sleep. Different from feeling tired due to lack of or interrupted sleep at night, persons with hypersomnia are compelled to nap repeatedly during the day, often at inappropriate times such as at work, during a meal, or in conversation. These daytime naps usually provide no relief from symptoms. Patients often have difficulty waking from a long sleep, and may feel disoriented.*” (Exhibit 22 of Appeal Letter)

I imagine that this is a result to the other two diagnoses. I typically require several naps per day due to the cognitive and physical fatigue I experience.

DISABLING CONDITIONS OBJECTIVE MEDICAL EVIDENCE

Because they only performed a limited review of my case, both the Case Manager and the “Physician Advisor” missed the significant Objective Medical Evidence in my file. However, to make a thorough and reasoned review of my condition, it requires a) actually being looked at, and b) understanding and evaluating it properly. In it’s irresponsible rush to terminate my benefits, neither of which was done.

The diagnoses I received by medical experts were determined not only by evaluating subjective complaints and their assessment of the validity of those complaints through in depth discussion and evaluation, but also by significant Objective Medical Evidence. Some of this Objective Medical Evidence included not only direct evidence of debilitating conditions, but also extensive supporting evidence. Among the objective medical evidence contained in the claim file and accompanying my appeal are the following:

PRE-TERMINATION:

- MSLT(August 2003) – Dr. [REDACTED]
- Neurocognitive Evaluation (July 2003) – **David A. [REDACTED]**, Ph.D.
- Tilt Table Test (October 2003) – [REDACTED] Hospital.
- Functional Capacity Evaluation (January 2004) – National Rehabilitation Hospital.
- Neurocognitive Evaluation (May 2004) – [REDACTED], Ph.D. (*IME arranged and paid for by [EMPLOYER]*)

- Neurocognitive Evaluation Follow Up (May 2004) - [REDACTED], Ph.D.
- Neurocognitive Evaluation (May 2005) – [REDACTED], Ph.D. (*IME arranged and paid for by [EMPLOYER]*)

POST-TERMINATION:

- Neurocognitive Evaluation (May 2007) – [REDACTED], Ph.D.
- Tilt Table Test (June 2007) – [REDACTED] Hospital.
- CardioPulmonary Exercise Stress Test (July 2007) – [REDACTED], M.D.

The combination of the objective medical evidence and all other input, has led *every medical professional that has examined me since May 2003*, including those arranged and paid for on behalf of [EMPLOYER], to the same diagnosis. Each has also concluded that my conditions preclude me from being in a position of sustaining gainful employment of any sort, much less at the level required by my LTD contract.

Not included in the above list are the extensive medical tests that ruled out other possibilities. These are listed separately in a copy of the document originally submitted as part of my initial disability claim.

DEBILITATING CONDITIONS

While I suffer from numerous difficult symptoms, the ones which cause me the most difficulty in terms of normal functionality are excessive fatigue and severe cognitive deficits. As has been shown to be the character of the diagnoses I have received by nationally recognized experts, these conditions are variable in their severity on any given day. Some days I may feel at 60% of my pre-illness functionality, and some days at 30% of my pre-illness functionality. It is just as likely to change hour to hour to that extent as well. Since the onset of this illness, I can't say that I've ever had a moment that I was more than 70% of my pre-illness functionality.

Make no mistake about it; I am not an idiot or an invalid. The Neurocognitive evaluations all rate me as being a reasonably intelligent person. I do not need a wheelchair to get around. If my condition at any given time allows it, am capable of coherent conversation, going out, interacting with my children's teachers, and even going 'across state lines'. My disability policy does not require me to be in a vegetative state. It does however require that I "*be incapable of performing the requirements of any job for any employer*". This would require that I be available forty hours a week on a consistent and reliable basis. This I am not able to do as is evidenced by overwhelming objective medical evidence in my case.

The conditions that prevent me from being able to participate in an employment situation on a sustainable and reliable basis are:

Excessive Fatigue. The fatigue comes in two forms, physical and cognitive. They are separate and distinct yet I am usually suffering from both of them all the

time and when they are out of synch, it is really disruptive; it is really hard when I am cognitively very fatigued but my body doesn't want to rest or vice versa.

I typically nap several times a day. They are rarely at the same time; it just depends on how my body is dealing at any given hour.

While it is hard to show that one is mentally or physically tired, there is nonetheless substantial objective evidence of it in my case file to support the actual evidence of this symptom.

- The MSLT of 2003 diagnosed 'Hypersomnia',
- Every professional performing other tests, such as the Neurocognitive Evaluations or the Functional Capacity Evaluations have noted my increased fatigue during the duration of the testing. This has been universal and consistent, including from the professionals hired by [EMPLOYER].

Efforts to treat this fatigue with everything from stimulants to supplements have been unsuccessful. While some treatments have had some level of benefit, they have either been minimal or beneficial for only a brief period of time.

If I am too tired to take out the trash, well it just will have to wait until next week. However in a work environment if I am too tired to complete a report or attend a meeting, it is a significant problem for my employer and to my continued employment.

Cognitive Deficits – The universally consistent commentary of the four Neuropsychologists that have personally tested me speaks for itself. Perhaps the best summation of the cognitive problems is by Dr. [REDACTED]. Dr. [REDACTED] is a Neuropsychologist that I was sent to for an IME by [EMPLOYER]. Dr. [REDACTED] stated in her report (Exhibit 8 of Appeal Letter) after a very comprehensive multi-day testing session that *"The principle areas of dysfunction shown by the patient appear to be in the area of marked visual-motor difficulty and information processing speed and efficiency, with marked reductions also in the patient's retention skills and general perceptual-motor problem solving effectiveness."*

Remember now, Dr. [REDACTED] was hired and paid for by [EMPLOYER] to determine the validity of my complaints and to determine if I was able to return to a work setting. She was provided all data [EMPLOYER] had compiled on my condition, including the opinions of internal [EMPLOYER] IDSC physicians. This testing spanned over two days and she was tasked with doing a thorough review of all medical and other evidence in my file. In her conclusion she unequivocally stated *"his impaired concentration, poor and incapably compensated mode of behavior and thinking combine to make him a very poor candidate for any kind of work."*

I am lost when the Neuropsychologists start discussing 'hippocampal gyre', 'spatio-temporal context', and 'fronto-subcortical CNS', but I understand all too well the practical implications of my condition:

- I might go to the refrigerator to get out a tea bag, notice the grapes and reach for them, and then stand at the refrigerator for a minute or two trying to remember what it was I actually went to the refrigerator for. I may or may not end up remembering the tea bag and am as likely to end up giving up as not.

- I might walk into the Woman's room at a rest stop instead of the Men's (*now that was pretty embarrassing!*).
- I might be in the middle of a conversation and forget what I was discussing (*countless times per day*).
- I might be upstairs in my room only to eventually have the smell of something burning remind me that I had put something on the stove before I went upstairs and became distracted, forgetting I had started cooking something.
- I might excuse myself from some company to do something quickly, and then become preoccupied with something else and forget to go back.
- I might unload the groceries and later in the day not be able to locate the shampoo I had purchased, only to find it two days later in the refrigerator.
- I might call someone and forget why once they have answered.
- I might not properly register daughter up for Philosophy class and she ends up being stuck taking the "Drama Appreciation" class (*fortunately we got that one straightened out!*).

Everyone has these 'senior moments' from time to time, but I suffer from them many times a day, sometimes all day long, and that is when I am in non critical, resting situations, I can not imagine how I would be able to deal in a work environment. If I lose track of what someone is discussing with me in a book store or social setting, it's embarrassing at most. If I do that in a work environment, it will be a significant problem. I have tried cognitive behavior therapy techniques, but when one becomes very easily mentally fatigued and can't easily multi-task, even those don't work.

Translating those into an employment situation, can you imagine someone working at the level Sedgwick has proposed and forgetting that there are people awaiting him in the conference room he just left? Or not being able to have discussions that are not interrupted by complete loss of track of thought? I don't want to even think of the potential problems for an employer if I wonder into the Woman's rest room by mistake!

As I understand it, my language, perceptual, and motor functions are with normal limits, as is my memory, although apparently that is not accurate on a demographically adjusted basis. Apparently, as I understand it, the underlying problems are with the processing of information and the resulting 'functional' use of those capabilities. Dr. [REDACTED] (no relation), arguably the nation's foremost neuropsychological expert in the cognitive impact in patients with Chronic Fatigue Syndrome, noted that my "*contributing factors likely include poor sustained attention and slowed information processing speed affecting encoding and retention of information. Combined these functions will preclude Mr. [REDACTED] from concentrating and paying attention long enough to encode several pieces of information into memory. In addition, he will have difficulties to absorb and encode information efficiently.*" (Exhibit 6 of Appeal Letter). Unlike the case manager and the other representatives from Sedgwick, Dr. [REDACTED] actually performed a 'thorough and complete' review of all relevant documentation in my case, including the five evaluations and other medical data.

Dr. [REDACTED], consulting Neuropsychologist to [Initial TPA] on my case, when discussing my case with the [Initial TPA] Vocational Expert stated that I “*likely would have difficulty with thinking speed and concentration.*” The other consulting neurologist for [Initial TPA], Dr. [REDACTED], apparently supported my claim as well. This is according to various comments in the file about his report; Sedgwick has to date failed to produce this report for my attorney despite requests for that specific report.

Neuropsychological Evaluations are considered Objective Medical Evidence; there are five of them and **they are all consistent.**

Disorientation. Like fatigue, disorientation comes in both physical and cognitive forms. For example, if I turn around too quickly, or kneel down inappropriately, my balance will become unstable and I will need to hold on to something. Cognitively, the sense of disorientation is a sense of confusion as I am having difficulty trying to process something I’m seeing. For example, one day I was watering the vegetable garden, as I have done many times. This particular day I came around to one section of the garden from a different angle than usual. I saw two bushes that I didn’t recognize and I couldn’t figure out where they came from. Had my brother-in-law just planted them? It took a couple of minutes for my mind to catch up with my eyesight and, after putting the entire scene in perspective, I realized that they were the same two plants that I had watered countless times before, just from a different angle. Can this be captured on surveillance video? I think not!

The physical disorientation has been a matter of learning how to manage my movements to minimize the physical effects. There really isn’t much that can be done about the cognitive disorientation; I have to deal with them as they happen, taking my time and getting myself re-oriented.

The objective medical evidence supporting this includes the multiple tilt table tests, Neuropsychological Evaluations, and functional capacity evaluation.

I am burdened by these symptoms all day, every day. It is merely a matter of degree at any given time as to whether I am reasonably articulate and alert or can’t pull together a coherent sentence or need to excuse myself for a nap. Unfortunately, none of these are discernable to an observer, especially through grainy video tape. This is why I have been *extensively* examined by professionals who are specifically trained, and in some cases are leading experts, in the underlying medical and neurological conditions causing these issues. An Occupational Medicine physician with a specialty in ‘Health in the Arts’ and a nurse case manager are simply not qualified to make judgments on these issues.

PERSONAL ACTIVITIES

After the very demanding work environments I have had over the last twenty years, I find it very difficult to deal with the limitations I currently face due to the fatigue and try to keep myself as busy, both cognitively and physically, as I am able to within the bounds of my illness. I have always understood that individuals with chronic illnesses

should keep as physically and cognitively active as possible to prevent muscle and brain atrophy as well as depression.

This has been confirmed by my physician, Dr. [REDACTED], as well as the numerous Neuropsychologists that I have seen, including those arranged and paid for on behalf of [EMPLOYER]. All professionals I have dealt with, including those retained by [EMPLOYER], have recommended that I keep as busy as possible within the bounds of my illness. I have been honest and upfront about my activities to ensure they are approved. Most notably these activities have included volunteering with the local youth recreational league during basketball season. I also attempt to perform as many daily activities, such as grocery shopping, being involved with my children, cooking, attend parent/teacher conferences and other general activities as I am able based on how my illness is affecting me at any given time.

The nature of CFS is that the symptoms are highly variable in both severity and occurrence. As Dr. Renee R. Taylor, Clinical Psychologist nationally recognized leading CFS researcher, and Professor of Occupational Therapy at University of Illinois at Chicago (UIC) notes in her book "Clinicians Guide to CFS" notes, "*the enormous variation in symptom severity that can allow patients to be relatively functional for brief intervals yet severely impaired is very difficult for others to comprehend.*" (Exhibit 22 of Appeal Letter)

This explains why, whenever I do anything of substance, including simple shopping or driving my kids somewhere, I must 'pace' myself to allow for the expenditure of the energy to do so. Pacing of activities is the most effective means of managing CFS. (Exhibit 22 of Appeal File.). This is further explained in Dr. Lapp's statement of my condition. This applies not only physical energy, but cognitive energy as well.

Professor Anthony J. Pinching (Professor of Immunology and Head of the Chronic Fatigue Services Clinic at St. Bartholomew's Hospital in London) describes the fatigue associated with CFS "*One of the characteristic features of CFS/MDE is the delayed way in which setbacks can occur after attempting too high a level of activity.... It becomes important to know from experience what activities are manageable without setbacks so as to determine a current baseline of sustainable activity. It is important to take account not only of physical activity, but also of mental and emotional activity – the latter are often the most consuming of energy for people with CFS/ME. At all stages it is important to have a balance between different types of activity, especially between "have to do" and "want to do" things.*" (Exhibit 22 of Appeal File)

As a result of this variability, over the last five years I have learned to be flexible with my commitments so that I can do things as my physical and cognitive symptoms allow. Often times I would have to cancel something I had planned because my illness did not allow me to do it at that particular time. Other times I feel better and appear to the casual observer as being fully healthy; unfortunately things like general brain fog, disorientation, and other symptoms are always present, it is just a question of to what degree at any given point in time.

I attempt to be involved, to the extent that I am able to, in as many 'activities of daily living' as possible. I do this not only to minimize the stress on my family of have

me only laying in bed all day, but also for therapeutic necessity. All doctor's I have seen, including the IME doctor's arranged and paid for on behalf of [EMPLOYER], have recommended that I keep as active as possible within the bounds of my illness. I have discussed these activities with these doctors and received appropriate guidance.

It is widely known that remaining stagnant while chronically ill results in muscle and mental atrophy. According to the Centers for Disease Control (CDC), it is *"important not to avoid activity and exercise altogether. Such avoidance leads to serious deconditioning and can actually worsen other symptoms."* They note that *"CFS patients must learn to pace activities"* and that *"The goal is to balance rest and activity to avoid both deconditioning from lack of activity and flare-ups of illness due to overexertion."* (Exhibit 22 of Appeal Letter).

Specifically, Sedgwick notes that they observed the following activities and that they feel that these activities are 'inconsistent' with my 'alleged symptoms':

1. **Driving extensive distances** – Once again, I am not in a vegetative state. I don't drive at all, even down the street, if the state of my condition at any given time I feel I can not do so safely. Since my illness, I drive much more cautiously than I used to, primarily because my thought processing speed is greatly reduced (as shown very clearly in my objective medical evidence). Generally I drive safely, although I have been known to change lanes inappropriately or drive well below the speed limit at times.

I use my best judgment prior to going anywhere as to whether I should be driving or not, both in terms of my cognitive as well as fatigue functioning. In terms of distance driving, it is the same. If it is a drive expected to be more than an hour or so, I will typically take Provigil to be able to stay alert. Provigil, however, taken only on occasion, will keep me up two nights, so I tend to avoid its usage. Unfortunately, when used on a regular basis, Provigil has proven to become ineffective. I might drive distances of an hour or more maybe once every few months, usually something for one of my kids. This is my daughter's junior year in high school, so I suspect I'll be visiting a few colleges with her. She will, in all likelihood, be doing most of the driving however.

In the particular circumstance that Sedgwick pointed out, I drove my son to [REDACTED], about an hour away. According to the surveillance, on Saturday March 31, I was observed once, exiting my house in my bathrobe and retrieving my cat from a neighbor's yard (I live in a town house so it was not a far walk). On April 1, I drove to the baseball event (a 'Fanfest'), and on April 2, I was observed once all day, driving my daughter to her school, which is a mile away. I was not seen again leaving the house. Per the entry in the claim file "2 out of 3 days EE did not leave his residence; however, on Sunday 4/1/07, EE was observed to drive approx 57 miles across state lines to [REDACTED] to attend a baseball game. No other activity of significance was obtained during the othe two days of surveillance."

Understanding the nature of my illness, it is clear that this is not in the least bit 'inconsistent' with my complaints. To begin with, I rested the entire day before to have enough energy for the trip. The day after was spent recovering from the trip. In addition, during the trip I got confused finding the parking

lot, found a spot at the event to sit and rest (often napping) while my son participated in the event, and upon returning that afternoon, went straight to bed (see attached email exchange with my sister). This behavior is entirely consistent with the nature of my symptoms in context with my illness.

I am not sure why the case manager was so eager to point out that I even was capable of going “across state lines”. I’m not sure how it is where she is, but crossing state lines has never required any additional effort, at least not that I was aware of. The [REDACTED] state line was ten minutes from my house. Where I am now the [REDACTED] state line is five minutes away. I’ve never noticed any ill effects or significant physical or cognitive difficulty when driving across those lines and have been unable to locate any medical research on the issue.

2. **Volunteer work** – I have been very clear with all treating medical professionals of my volunteer activities. I identified this on my initial application for LTD in 2004. These activities required minimal time requirements and were done on very flexible basis, allowing me to engage in these activities only as my illness allowed at any given time. Had the Sedgwick case manager inquired for clarification, I would have happily shared this information with her with the actual circumstances and in context with my symptoms and illness.

I performed the following activities for [REDACTED]:

- a. Director of Referees – this lofty title basically required that I publish a list of the games on an online system at the beginning of the season. This takes a few hours². During the season I just check to make sure that referees have appropriately self assigned themselves. Occasionally I have to call some of them up or send out emails to make sure games are appropriately covered. From time to time I would get confused about game coverage and either no referees would be assigned or too many assigned. This role was usually performed from my bed and typically required three to five hours per week. It was done in increments of time that were manageable within the bounds of my illness. Sometimes this would consist of a few minute phone call, sometimes longer, but at no time more than 30 minutes at a time.

When I first read the ‘typical’ description of duties supplied by Sedgwick, my reaction was *‘if that was my job then I failed miserably!’* The reality is that my actual duties are a fraction of those described. Once again, had the case manager been looking for the truth of the matter, I would have happily provided her that information as well as directed her to the head of the basketball operations if she had any further questions.

- b. League Director, 11U Boys – This role was trivial. Apart from setting up the schedule at the beginning of the season (see attached template for exactly how complicated this was), hosting an ‘evaluation’ session one

² Exhibits 18-23 of counsel’s Appeal Letter support the minimal time commitments and skill levels required with this position.

night pre-season (2 hours), hosting a draft session with the coaches (2 hours), and making sure that the ball and time clock was in the hands of the appropriate coach (0.1 hours), there really wasn't much to it. There were very few issues that needed to be dealt with. It rarely took more than an hour a week.

c. Coach, 11U Boys – the league was short a coach, so I filled this role, but not very well. I was not able to make it to either all the practices or all the games and parents would fill in for me. When I did do both it took up 2-3 hours per week. My team lost every game by 20 points or more.

d. In order to get some physical exercise in, I also tried to referee a couple of games each weekend. This was in the younger leagues so there was minimal activity and I could rest often. Refereeing at this age group usually entails walking back and forth along reduced sized courts and stopping play from time to time to helping the kids learn the rules, such as double dribble and lane violations. The amount of time I was able to do this varied depending upon my fatigue level, but generally was about 2 ½ hours per weekend. My physician, Dr. [REDACTED], encouraged me to do this.

e. In total, I averaged 5 to 10 hours, usually less, and very occasionally slightly more, per seven day week during the season. Any activity was only as my illness allowed. The director positions were usually done via phone and computer from my bed and are in no way analogous to work one would do in a paying position. I had no meetings I needed to make, no time commitments that could not be easily modified if my illness required. The volunteer work never kept me from taking the 2-3 naps I usually take each day due to either physical or cognitive fatigue. On Mondays and Tuesdays I was usually exhausted from those 5-10 hours and I rarely got out of bed during those days.

f. I did the majority of this activity on laptop and phone from bed. You see, the nature of my medically documented decreased blood volume makes even sitting difficult at times. If the case manager had bothered to read the Functional Capacity Evaluation that was performed in 2004 and was in my case file, she would have read part of the conclusion that stated *“Unpredictability of the patient’s heart rate and blood pressure response to activity, whether sedentary or active affects his endurance, his ability to complete tasks and his ability to perform consistently to a significant extent.”* (Exhibit 32 of Appeal Letter.) Laying in bed makes this somewhat less of an issue as my blood does not pool to my legs and the heart/brain malfunction of NMH is not as much of a factor. The case manager might also have been interested in the next sentence, *“This will undoubtedly have serious impact on his ability to return to competitive employment.”*(*Id.*) The responsible thing to have done would have been to pass that along to the Physician Advisor as well. That would have been ‘careful and thorough review’.

g. This activity, a way of feeling useful in an otherwise stagnant life due to my physical and mental fatigue, was very therapeutic to me. After I learned of [EMPLOYER]’s decision to terminate my disability benefits due to this activity, I thought about what I would have done during that time if I had not been volunteering. It was a very distressing thought just how empty

things would have been in my life during that period. I now understand more fully why all the medical and psychological experts recommend keeping as busy as possible.

h. I plan on performing the Director of Referees position again this year, but not the others as I will be in [REDACTED]. Once again, I'll spend a few hours (over a couple of weeks) entering the league schedules and checking the online self-assign system several times a week during the season to make sure the games are covered, maybe make a phone call or two if one isn't. I'll also probably send out a mass email prior to the season to recruit more referees. If I get any, I'll need to spend about three minutes each entering their information and maybe another couple of minutes sending them an email. I can do all this from the comfort of my bed in another state, without even any need for the challenge of going 'across state lines'.

The case manager did not inquire with me or anyone else involved in these activities to gain perspective and to make sure she had all the relevant information in order to make a truly objective analysis to obtain the truth behind my illness. I don't mind her questioning my activities, I would have been happy to have answered any questions she had. I have nothing to hide and have always been open fully open and cooperative. I do mind her making subjective judgments based on incomplete information and making no effort to obtain appropriate information. Such action shows bad faith and complete disregard to reaching objective conclusions.

Other activities I participate in, at least to the extent I am able to at any given time, include:

Cooking – I have always enjoyed cooking, and on any given day, if I have both the physical and cognitive energy, I might be able to pull together a decent meal. However, I often plan to cook dinner, but find myself too exhausted to be able to. It is not unusual for me to get confused during a recipe and have to start from scratch after messing something up.

Writing – I have always been a prolific writer as well as being very creative. I wrote a book, but it became very complicated keeping the tenses and characters straight. It took me longer to fix all my errors than it did to write it to begin with. Unfortunately the therapeutic value of writing it was well out weighed by the mental exhaustion of dealing with all the inconsistencies in it. As with any artistic creation its value is really in the creation of it, in my case therapeutic value. Due to my concentration problems, I've not been able to read it start to finish, but my mother tells me it flows well. I'm afraid it's probably right up there in terms of quality as your in-laws painting of the family dog that your spouse insists on hanging up in the den and will probably end up in a garage sale some day. Writing is a common exercise for those of us with CFS as it is something we can do while lying on a sofa or bed in bits and pieces as our physical and mental energy allows and allows an outlet for our creativity, which still exists despite our illness. Sometimes this is a few minutes, sometimes this is longer durations. I recently was directed to an article where the author, a CFS patient, discussed the issue by stating *"writing can nurture the spirit and enhance the quality of our daily lives in spite of illness and disability. By nurturing our creativity, we can feel and appreciate our aliveness, regardless of the limitations of our bodies."* (Exhibit 22 in Appeal File)

Exercise – As I previously stated regarding my volunteer activities, I would referee the young children in the local basketball league. It really was about as much exercise as walking the dog though. I did try Yoga, but found myself not being able to make it to many of the sessions as I was unable to on many days. I may try to pick it up again at home using a DVD. I have been working on graded exercise techniques, with limited success.

Chores around the farm – including feeding the horses, basic gardening, and other miscellaneous activities. One day I washed two cars, I was beat for the rest of the day and the next day as well. Sometimes a few bales of hay might need unloaded and stacked, I help out if I can. The other day some rocks needed to be loaded on to a pickup truck and I offered to help, I lasted about five minutes before I had to go inside and lie down.

Travel – I'm not sure why the case manager thinks this is a big deal. A trip to New York requires a) a ride to the train station, b) waiting at the train station for the train to board, c) sitting on a train (often napping) for a few hours, c) taking a cab to my destination. Flying somewhere doesn't require much more effort, patience maybe, but most of it is sitting and waiting during which one can rest as needed. I am always extremely exhausted after any such trips. That doesn't mean I can't do them as long as I have rested up for them and take Provigil if appropriate. The case manager also made a point that while visiting family in [REDACTED] I would be going to different family member's houses from time to time. She had no way of knowing a) how often, b) how far apart they were, c) how I was getting there, or d) any other information on it. For all she knew I hired a private ambulance to take me from place to place and I only did it once a week. Or maybe they lived next door. The point is, she didn't know, she didn't inquire, she simply assumed and made inflammatory statements in the file about it being 'inconsistent' with my complaints. Travel is not inconsistent with my symptoms or illness. It is 'difficult', but not impossible or even 'inconsistent'. I rest prior to and after a travel day and I give myself plenty of time in case I have cognitive boo-boos or need to stop to rest. I travel only occasionally, and often see handicapped or otherwise disabled people doing the same. See article on travel for people with CFS in Exhibit 22 of Appeal Letter.

'Interacting with multiple vendors' – yes, I do manage, and will continue to manage, buying donuts, paying for gas, even taking my daughter shopping. I fail to understand how the one internal [Initial TPA] physician (non-specialist) Dr. J [REDACTED] felt that this ability to 'interact with multiple vendors' after reading the surveillance reports of me occasionally taking my daughter to Dunkin Donuts, buying gas, and taking my wife to lunch can be related to the ability to perform in a work environment, especially a cognitively challenging one. If this were the case, it would seem to make sense to set up hi-tech recruiting stalls at local Exxon stations. I guess when insurance company reviews pay so well it's hard for these 'professionals' not to tell them what they want to hear, no matter how ludicrous.

Many more activities of daily living – I water a neighbor's plants, I'm helping my daughter get a house sitting service started, I'm housetraining two puppies, and on and on. However, I do each of these at my own pace as my illness allows, which many days is not at all, and if there's an extra puppy accident or two in the house, we'll just have to deal with it.

CLOSING COMMENTS

I understand the nature of this disability insurance. I understand that there are people trying to defraud their insurance plans, and I understand the need for insurance companies to protect themselves, their clients, and their shareholders. However, this is a contract and sometimes they do have to pay out on legitimate claims, such as mine.

My attorney lays out the misdeeds of the case manager and physician advisor quite clearly. Reasoned review of the process that took place can only conclude that it was irresponsible at best. Quite frankly, the terms unethical and incompetent are what come to mind with more confidence.

This termination and appeal process have so totally disrupted mine and my family's life to an immeasurable degree in ways that the reader of this document can only imagine. If the termination were in fact based on a thorough and reasoned evaluation in a competent manner, I guess it would be easier to deal with. However, when one is put in such a precarious position and is forced to spend so much money to correct something that was so horribly bungled by those that are trusted with this great responsibility, it is very difficult to reconcile.

There really are only two possible conclusions to be drawn from Sedgwick's handling of this case, and neither of which is very comforting. Either there was deliberate intent to terminate my benefits regardless of merit or I have been dealing with the 'Keystone Cops' of claims administrators.

FURTHER AFFIANT SAITH NOT:

I hereby affirm under penalty of perjury that the foregoing is true and accurate to the best of my personal knowledge, information, and belief.

September 25, 2007

DATE

