

October 13, 2010

Dear Distinguished Members of the CFSAC,

My name is Marly Silverman, you already know me as the founder of Patient Alliance for Neuroendocrine-immune Disorders Organization for Research and Advocacy, also known as P.A.N.D.O.R.A., Inc.

I appreciate this opportunity to share with you my personal insurance disability story under ERISA, also known as the Employee Retirement Income Security Act. It all started in 1998 shortly after being diagnosed with CFS-ME and fibromyalgia. It had taken me just about 13 months to find the correct diagnosis. While I was lucky in that respect, my ERISA insurance disability story is typical of the sad and tragic stories we often hear from our patient community. It is unfortunate, 12 years later, as a patient advocate and founder of P.A.N.D.O.R.A. I continue to hear similar, heartbreaking stories from CFS-ME patients across the U.S. dealing with ERISA disability issues. These stories as well as mine, all touch on the quality of life issues or lack thereof, that CFS-ME patients experience 24/7, 365 days of the year.

When I look back at that time in my life, I don't even know how I did it. How did I survive one of the toughest personal battles I have ever faced at a time when I was most vulnerable? I suppose it was sheer determination, resilience, persistence and should I say great luck in having access to an outstanding physician in Florida, Dr. Nancy Klimas, coupled with the unconditional love of family and close friends, who are still great supporters of my personal plight.

I was a junior officer for a major U.S. bank working in Miami, Florida and representing this bank in the countries of Brazil and Portugal. It was an exciting career, and one in which I quickly immersed myself with great personal and professional satisfaction along with the solid financial rewards brought in by hard work and salesmanship.

Since I was by all standards a savvy financial consultant, I had in place insurance policies that would cover my family and I, in case of death, accident, short and long term illnesses and disability. I also had a good medical insurance policy through my employer. I thought I was prepared in case of financial adversity, but the reality set in rather quickly, after diagnosed with CFS-ME, when I found out in fact I had no longer financial stability and safety.

I was not even prepared for what ensued shortly after I became ill with ME-CFS. Little did I know what I would have to endure. It never occurred to me that one of my toughest challenges would come directly from the disability insurance companies I trusted to ensure my financial stability. My professional training and knowledge assured me that the financial plan I had built up would prevent me from becoming a welfare number case and/or in the worse scenario: homeless. Except that all that I professionally knew, became just a theory. The reality was cruel, and harsh. I could not escape the irony of

seeing it all crumbling down, the same financial safety net that experts at the bank I worked for, assured me would kick in if adversity or crisis sets in.

After a failed attempt to return to work, my employer told me that I “had no choice but to file for long-term disability”. They simply could not accommodate the challenges CFS-ME brings to the work environment.

Faced with the inevitable, I begun the complex bureaucratic process of filing short and then long-term disability insurance under ERISA, also known as Employee Retirement Income Security Act. This process is mind-boggling, confusing, contradictory and simply unfair to ME-CFS patients. I remember filing forms after forms that expected me - a sick patient – to describe what is to have in many instances an invisible illness. The burden that they place in the sick and disabled employee is mind-boggling. Your treating physician opinion does not count. What it counts is the opinions of their medical reviewers whom have never treated or saw you in person, to make the final judgment or to decide if you are disabled or not.

The regulations of ERISA are excessive and extremely bureaucratic. They are part of an “administrative process” that uses language or legalese, which is often contradictory and counter-productive to the well being of the claimant, i.e. the individual who is sick or injured. This administrative process is long, and tiring. One must exhaust all of the steps in the administrative process, before one is allowed to file a suit against the employer/insurance company. By the time one is actually able to do this, personal savings are gone, and a financial crisis of long-term proportion sets in. Statistics show that for CFS-ME patients it is almost impossible to financially recoup from such harsh losses, leading to a life-long substandard quality of life.

In my case, in order to assist me, I had the counsel, of at least three very good Florida attorneys who throughout the process, read, misinterpreted or simply missed on the interpretation of the regulations or contents of my employer’s ERISA policy, which at that time was administered by Liberty Mutual.

First the policy required for me to file for Social Security Disability, which I did diligently. When I was found disabled by Social Security, my employer ERISA insurance company quickly dropped me after they were reimbursed thousands of dollars from the payout I received from Social Security retroactively.

Soon after they received their full reimbursement, which I was forced to do with threatening demand letters, they sent me a letter stating that “I was never disabled to begin with”, and that they would not continue to pay for my disability benefits. The additional hardship of such action was the fact that I no longer would have group employee health insurance benefits, my work pension stopped accruing, and I lost a significant financial support needed to pay my medical bills and my household bills. Sick, disabled and now helpless was then my new status.

The game these insurance companies play is Deny, Deny, Deny, until the claimant gives up or as in my case; an attorney misses the appeal deadline due to the convoluted set of administrative rules they provide in the ERISA employee manual. The policy regulations language were so complicated, and one of your distinguished members of this committee can attest to that too, that not one single attorney in my case could really interpret or state for sure, after the fact, when (the timeline) and what the appeal policy requirements really were in my case. The end result was that the deadline for appeal was missed and I never had the opportunity to redress my grievances. This is plain wrong!

Meanwhile, the harassment from Liberty Mutual representing my employer was borderline criminal. They hired private investigators to follow me. Often I would see unmarked cars with tinted windows parked in front of my house or across the street, using technology that one would see it in spy novels or Hollywood movies. Liberty Mutual kept records of how long I stayed home, when I went to the doctors, when I attempted to shop for food at the supermarket. They took pictures of my family and I going to our synagogue. They even followed and recorded a film of the wrong person, alleging that I was working for an attorney in Broward County. Mind you that this young woman was at least 15 years younger than I, but matched the description of being “fit and slim”, which according to them was the “perfect picture of health”.

I had one psychiatrist hired by them, to tell me that I was ill because I “fixated in my illness”. I had a Liberty Mutual insurance investigator, while in unexpected visit to my house, asking me if she “could pray for me and if I accepted Jesus as my savior I would be cured”. In one occasion as I once again was driving and got disoriented going to a doctor’s office for an independent evaluation, they stated in their report that I was trying to “confuse them”. All of their efforts came to my full knowledge when we submit them a request for all of their records during the “administrative process”

These attempts were simply trying to prove that I “was not disabled” and specifically implying that I was committing fraud, because they believed and continue to believe that CFS-ME is either a psychological illness or “does not exist”.

Liberty Mutual also attempted to communicate with another disability insurance – the one covering my private disability benefits suggesting that they too take action against me. Fortunately this insurance company acted honestly and has stood by me providing me with the benefits for the protection that I purchased month after month during my working years.

One of the most serious consequences when ERISA insurance companies deny disability benefits is the lack of access to the employer’s group medical insurance at a substantial savings for the disabled employee. As the disabled employee is forced to go into Cobra and without having the financial means to do so, what usually happens is that the disabled ME-CFS employee ends up without medical insurance, often being forced to go on welfare, food stamps and Supplemental Security Income, also known as SSI trying to get Medicaid.

Often patients with CFS-ME lose their homes, their savings, and the support of their families. Every day I receive e-mails or phone calls from CFS-ME patients sharing their personal nightmare. I am told of patients being abandoned by their spouses, fiancés or significant others, who are unable to handle the financial and the emotional hurdles the family faces. Often I hear of messy divorces where the healthy spouse accuses the sick spouse of having a psychological or psychiatric illness and therefore unfit to take care of their children. If you are a child whose mother or father has CFS-ME, your loss is doubly harsh.

While these personal stories, mine included, begin with a CFS-ME diagnosis, the quality of life issue is augmented by the cruel denial of disability insurance and sadly supported by employers and by medical providers too. How can anyone then make ends meet when receiving the average SSI, also known as Supplemental Security Income payment, a government welfare program, which averages \$375 dollars a month? How can someone provide for one's family?

It is time for ERISA regulators to address the inequities found in the ERISA disability as it applies to illnesses as complex as CFS-ME. One regulation I suggest be placed is to require employer ERISA insurance companies, specially when they deny disability benefits, to continue to provide the disabled employee with the same access to the employer group medical insurance, until said disabled employee is approved by Social Security Disability and only when eligibility for Medicare, which only comes after 24 months, is available. By doing so, it will be at a substantial savings for the sick disabled employee, especially when the ERISA insurance company is no longer providing a financial disability benefit.

ERISA needs to be revamped. ERISA is outmoded. I urge this committee not only to recommend changes that be made, but also to specifically outline how they can do it. I think it is important that we all push for similar and identical solutions as one Voice. We must do this together. Therefore I ask you to use this identical process to the other quality of life issues CFS-ME patients face continuously: the lack of medical care, the lack of qualified physicians to treat them, the lack of physician training in medical schools and the lack of substantial funding for CFS-ME.

The lack of quality of life has taken a toll on our community. For many years this community has lacked a strong political patient voice. No more! Times are a changing. We are witnessing a rebirth of our advocacy patient community. We are witnessing strong unity all across the land as patient groups of all sizes are uniting in one major point: **Getting enhanced quality of life for CFS-ME patients** and saying out loud.

I am proud to be part of this emerging rebirth. One specific effort is the ME-CFS Worldwide Patient Alliance, a grass roots cause project created on Causes on Facebook. In just about 2 months, this cause-project is now 1, 396 members strong. Donations are currently totaling \$8, 500. The goal is to create a cutting edge advertisement campaign from a patient perspective regarding quality of life issues. We hope to develop this into a strong political base, one that will assist you in getting your recommendations in place.

Lastly, as my distinguished patient advocate colleague Pat Fero, from the Wisconsin CFS Association has shared in her latest testimony to you: “research funding for CFS-ME actually went down from 24% in 2000 (GAO)” to a “paltry 5-6% currently. Now is the time for a strong resolve to find the answers, and aggressively increase funding and bring health to millions of Americans who are stricken with ME-CFS.

As One Voice, One Community, One Cause™ we can truly make a difference for millions of individuals here in the U.S. and across the globe.

Thank you for all that you do.

Marly C. Silverman