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**Sent:** Monday, January 18, 2016 6:35 PM

**To:** EBSA, E-ORI - EBSA

**Subject:** Office of Regulations and Interpretations, Employee Benefits Security Administration US Department of Labor in regard to RIN 1210-AB39

We represent [MEadvocacy.org](http://MEadvocacy.org) (a project of May12.org), a non-profit organization that advocates for patients suffering from Myalgic Encephalomyelitis (ME). ME is a serious neuroimmune disease, affecting an estimated 1 million Americans. About a quarter of ME patients are so disabled as to render them bedbound. The majority are disabled to the extent of being unable to work. Since there are currently no FDA-approved treatments for this disease, ME patients are left to suffer for a long time—some times for decades. Many of these patients are affected by ERISA, which governs employer-sponsored long-term-disability (LTD) insurance benefits. Patients have been negatively impacted by the existing law, which favors the insurance companies over the disabled claimants by denying jury trials and punitive damages, by providing, generally, an abuse-of-discretion standard of judicial review, by not recognizing and counteracting the obvious conflicts of interest of the disability insurance carriers and, finally—through the existing claims-procedure regulations—by permitting unreasonable, unjustified and obstructionist tactics by the insurance companies administering the claims-review process. We are therefore encouraged by the Department of Labor's proposed new regulations, which—although they do not and cannot legally address the issues of jury trials or punitive damages—do address in an effective manner the claims-administration process in a way that would bring a degree of fairness and objectivity into the claims-adjudication process and help balance the scales, which have been severely tilted against the claimants.

[MEadvocacy.org](http://MEadvocacy.org) supports the proposed changes because they have the potential to improve the fairness of the process, not just for ME patients, but for all who are vulnerable during a difficult time in their lives. Not only are these patients faced with difficult and painful life changes as a result of becoming disabled, but they are forced into an unfair battle they are ill-equipped to deal with.

Many of these patients have lost their battle to obtain LTD benefits necessary for a minimally acceptable standard of living. One such patient describes her lost battle as follows:

*I became disabled with ME in 2003. My employer had paid into my disability insurance for over 10 years. By the time I had to stop working, I was so disabled that I could not walk more than 20 steps a day. I could not stand for more than 2 minutes. My doctor was a world-renowned medical expert in my disease. He submitted extensive paperwork outlining the severity of my disease and he wrote a letter to my disability insurance company stating that I was too disabled to do ANY work and, furthermore, that he was not optimistic that I would ever be able to return to work. I had applied for Social Security Disability Insurance (SSDI) and after a complete review, including being seen by the Social Security Administration's doctor, I was approved for SSDI at first try. Yet, unexplainably, I was denied disability from my LTD insurance. The person who reviewed my case at my LTD insurance was a disabled person himself, but he had the ability to work and therefore was known to deny most claims*

*because he felt if he could work, so could other disabled people. None of the people reviewing my case had any knowledge of, or experience with, my disease, ME, and therefore could not understand how serious and disabling this neuroimmune disease can be. They simply disagreed with my own doctor who was an expert as well as the SSDI doctor without explaining what they were basing that disagreement on. After I appealed, I finally got their records and saw that they had spent a lot of money and time trying to find any basis to deny my claim rather than to fairly adjudicate it, for example by ordering an outside expert review. They had investigators watching me and looking into my social-network activities and yet, could not find any information proving or even suggesting that I was not disabled. At the end, I just gave up fighting because it was just making me sicker.*

The new proposed ERISA regulations, for example the new conflict of interest rules, would have helped ensure that this claimant received a fair review in her quest for LTD payments:

- The claims adjudicator who reviewed her case was hired by her insurance company because he was known by the industry to deny cases. It was not explained why the insurance company came to a different conclusion than the claimant's own physician as well as the Social Security Administration without even performing an outside expert review. With the new regulations, this would not have been permissible.
- The insurance company's case paperwork on this claim only became available to the claimant upon appeal. Had the proposed regulations been in effect, it would have been available upon denial and may well have facilitated a positive outcome for the claimant given the ability, under the proposed regulations, for the claimant to challenge the denial more effectively.

Please note, that twelve years later, this patient is still very ill and too disabled to work and yet, has not received a cent in long-term disability payments!

Another patient's battle with LTD was equally unfair:

*I had paid into LTD for 8 years. I became disabled in 2000. At the time I applied, I had been off work for 6 months and had not improved - I was still housebound and mostly bedridden. My first contact with the LTD carrier was when a case manager called me up and screamed at me "Why can't you work! I'm going to deny your claim!" Needless to say, this type of abuse and intimidation was extremely upsetting. My initial claim was indeed denied, with no explanation as to why. I hired an ERISA disability lawyer for the appeal. That was denied. We sued and went to federal court. I won my case - the court ordered the LTD insurance company to pay my claim as they had acted in bad faith on several issues. The LTD carrier appealed. Just as the case was about to go to federal court again (where I stood a very good chance of winning), we entered into a settlement - I received pennies on the dollar of what I should have been paid. Ironically, I submitted the same medical information to the Social Security Administration, which applies a standard much stricter than the "own occupation" standard that was specified in my LTD plan: the "any occupation" standard. Nevertheless, I was approved for benefits "on the record" at the ALJ level. The fact that I was approved for Social Security under this much stricter standard didn't matter to the LTD insurance company - they said it wasn't relevant to my claim.*

The new proposed ERISA regulations would have also helped this claimant:

- The claims adjudicator was obviously biased from the outset to deny the claim without first performing a thorough evaluation or ordering an outside expert review, and possibly may have received some kind of compensation for denying claims. The proposed prohibition of employing claims adjudicators based on their likelihood to deny a claim would potentially have prevented the baseless denial of this claim.
- The insurance company's paperwork on this claim was only available to the claimant after the appeal of the denial. With the proposed new regulations, it would have been available a step earlier—after the denial—and that might have aided the claimant in winning her appeal without going to court.
- The insurance company would have had to explain why it denied the claim, including why it disagreed with the treating doctor and with the Social Security Administration. It also would have had to provide to the claimant any internal rules, giving the claimant a fairer chance to respond after the denial.

These are just two examples of countless others who similarly were wrongfully denied their rights to collect on long-term-disability benefits that were promised to them through their LTD insurance policies. As the law stands today, a U.S. LTD insurance company has nothing to lose by denying claims because even if they lose, they only have to pay the amount of the claim plus, generally, attorneys' fees (which are not always fully awarded) without any other liability. Disabled claimants have an insurmountable road ahead of them to fight for what should legitimately be theirs. Many are in such a weakened and ailing state that it takes too much effort to continue fighting and the insurance companies count on that knowledge. They make it so difficult and draw out the process so much that many simply give up. This is not fair practice. MEadvocacy.org hopes that these new proposed ERISA rules will help even out the playing field and that, in the future, disabled claimants will not have to face such daunting, enervating and unfair obstacles in pursuing their legitimate claims and that the new regulations will lead, in more instances, to just outcomes.

Sincerely,

Colleen Steckel and Joni Comstock  
for [MEadvocacy.org](http://MEadvocacy.org)  
Members of the Advisory Board