

Miller, Diane M. (CDC/NIOSH/EID)

From: albert b. frowiss [frowiss@frowiss.org]
Sent: Tuesday, March 22, 2011 1:40 AM
To: NIOSH Docket Office (CDC)
Subject: "NIOSH Docket #209" and "42 CFR 81.30"

I favor CLL as a Part B cancer.

I'm an independent claims advocate, a lay person. I've completed roughly 700 cancer claims since 2008, all SEC cases under EEOICPA, as that is my sole focus. I do take a smattering of non-SEC cases which come to me, effectively as a *pro bono* humanitarian gesture, as 99% of them go to NIOSH and if they ever emerge from NIOSH, are denials. I currently have perhaps another 200 SEC cases pending. As such, I see a sampling of CLL cases. I've probably had to turn down about a dozen CLL cases over the past 3.5 years. Roughly 2% at most. Perhaps another dozen of my clients who had CLL at one point, later got another opinion and got approved for SLL or NHL.

In reviewing nearly all CLL medical evidence files the distinction between CLL and NHL and/or SLL often seems a distinction with no difference to the lay eyeball. Often my clients are initially diagnosed with CLL, then on a subsequent visit the diagnosis seems in limbo and might turn out to be NHL or SLL, or perhaps AML or CML, or the practitioner or oncologist or pathologist tosses it in the air and just opines on some array of differential diagnoses, and leaves us hanging with no definitive diagnosis. DOL claims examiners are betwixt and between. Some of the more compassionate CE's from compassionate Districts get a DMC who sways to the claimant side. Others from dictatorial hardliner Districts rule against.

I find it hard to believe that a seemingly minor (to me) chromosome rearrangement in one tissue sample, which appears different in another, really definitively defines whether CLL is radiogenic or not. Does anyone really know? Did Congress really want to lay down such a hard line and exclude a class of leukemia victims?

If the VA now accepts CLL, and if the NCI and WHO all now believe CLL is NHL, and radiogenic, doesn't it make sense that EEOICPA and RECP laws should coincide? I believe that is the leaning direction of your proposed rule, and I applaud that direction and hope it is enacted swiftly. It's a bite sized step which I think Congress can embrace without discussion, in contrast to the Draconian changes that some in Congress have proposed, especially the six state "downwinder" idea.

In my view, the sway of rulemaking should be in favor of accepting CLL as a Part B cancer.

This is about all I can add to the discussion. I don't think it will make anything more than a very minor financial impact. I believe it would be the right decision to eliminate the exclusion of CLL and let it be considered an NHL.

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