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On the VA site at we find outstainding news: Citation Nr: 1417108Decision Date: 04/16/14 Archive Date: 04/24/14 DOCKET NO. 10-47 164)DATE On appeal from the Department of Veterans Affairs Regional Office in Louisville, Kentucky THE ISSUE Entitlement to service connection for primary lateral sclerosis (PLS). REPRESENTATION Veteran represented by:Paralyzed Veterans of America, Inc.ATTORNEY FOR THE BOARD Nicole L. Northcutt, Counsel INTRODUCTION Pursuant to 38 C.F.R. 20.900(c), the appeal has been advanced on the Board's docket. The Veteran served on active duty from March 1963 to March 1965. This matter is before the Board of Veterans' Appeals (Board) on appeal of a rating decision in July 2009 of a Department of Veterans Affairs (VA) Regional Office (RO). In March 2014, in accordance with 38 U.S.C.A. 7109 and 38 C.F.R. 20.901, the Board obtained a medical expert opinion from the Veterans Health Administration. As the claim of service connection for PLS is resolved in the Veteran's favor, no prejudice has occurred to the Veteran even though the VHA opinion has not been provided to the Veteran or his representative. FINDING OF FACT The Veteran had 90 consecutive days of active duty and is diagnosed with primary lateral sclerosis, a variant of amyotrophic lateral sclerosis. CONCLUSION OF LAW The criteria for service connection for primary lateral sclerosis have been met. 38 U.S.C.A 1110, 5107 (West 2002); 38 C.F.R. 3.303, 3.318 (2013). The Veterans Claims Assistance Act of 2000 (VCAA) The VCAA, codified in part at 38 U.S.C.A. 5103, 5103A, and implemented in part at 38 C.F.R 3.159, amended VA's duties to notify and to assist a claimant in developing information and evidence necessary to substantiate a claim. As the Board is granting the claim of service connection for PLS, VCAA compliance need not be addressed further. REASONS AND BASES FOR FINDING AND CONCLUSION Principles and Theories of Service Connection A Veteran is entitled to VA disability compensation if there is a disability resulting from personal injury suffered or disease contracted in line of duty in active military service, or for aggravation of a preexisting injury suffered or disease contracted in line of duty in active military service. 38 U.S.C.A. 1110 (wartime service). Generally, to establish a right to compensation for a present disability, a Veteran must show: (1) a present disability; (2) an in-service incurrence or aggravation of a disease or injury; and (3) a causal relationship between the present disability and the disease or injury incurred or aggravated during service, also referred to as the "nexus" requirement. Shedden v. Principi, 381 F.3d 1163, 1167 (Fed. Cir. 2004). Service connection means that the facts, shown by evidence, establish that a particular injury or disease resulting in disability was incurred coincident with service, or if preexisting such service, was aggravated by service. This may be accomplished by affirmatively showing inception or aggravation during service. 38 C.F.R. 3.303(a). Service connection may also be granted for disability shown after service, when all of the evidence, including that pertinent to service, shows that it was incurred in service. 38 C.F.R. 3.303(d). Additionally, VA regulation provides that the development of ALS manifested at any time after discharge or release from active military, naval, or air service is sufficient to establish service connection for that disease if the Veteran had active, continuous service of 90 days or more. However, the presumption of service connection for ALS does not apply if there is affirmative evidence that ALS was not incurred during or aggravated by such service, or affirmative evidence that ALS was caused by the Veteran's own willful misconduct. 38 C.F.R. 3.318 (2013). Evidentiary Standards VA must give due consideration to all pertinent lay and medical evidence in a case where a Veteran is seeking service connection. 38 U.S.C.A. 1154(a). Competency is a legal concept in determining whether lay or medical evidence may be considered, in other words, whether the evidence is admissible as distinguished from credibility and from the weight of the evidence. Rucker v. Brown, 10 Vet. App. 67, 74 (1997). Competency is a question of fact, which is to be addressed by the Board. Jandreau v. Nicholson, 492 F.3d 1372, 1377 (2007). When the evidence is admissible, the Board must then determine whether the evidence is credible. "Credible evidence" is that which is plausible or capable of being believed. See Caluza v. Brown, 7 Vet. App. 478, 511 (1995), aff'd per curium, 78 F. 3d 604 (Fed. Cir. 1996) (the determination of credibility is a finding of fact to be made by the Board in the first instance). If the evidence is credible, the Board, as fact finder, must determine the weight or probative value of the admissible evidence, that is, does the evidence tend to prove a material fact. Washington v. Nicholson, 19 Vet. App. 362, 369 (2005). If the evidence is not credible, the evidence has no probative value. When there is an approximate balance of positive and negative evidence regarding any issue material to the determination of a matter, the Secretary shall give the benefit of the doubt to the Veteran. 38 U.S.C.A. 5107(b). Evidence The service treatment records do not contain a diagnosis of primary lateral sclerosis or amyotrophic lateral sclerosis. And the Veteran does not assert that he developed his current neurological disorder during service or soon after service. Rather, he asserts that his currently diagnosed neurological disorder, developed many years after service, is a variant of amyotrophic lateral sclerosis, entitling him to presumptive service connection pursuant to 38 C.F.R. 3.318. In 2004, the Veteran was diagnosed with primary lateral sclerosis and records through 2010 continue to refer to the diagnosis. In January 2009, a private neurologist stated that the Veteran was being treating for a motor neuron disease, which he characterized as "ALS (PLS)," indicating that PLS is a variant of ALS. The neurologist stated that the disease had a slow clinical progression. On VA examination in October 2010, a VA examiner in internal medicine stated that the Veteran does not have ALS, but rather PLS, indicating that the two diseases are separate clinical entities. The VA examiner noted that a diagnosis of PLS, not ALS, had been rendered by both VA and private neurologists. In order to clarify whether the Veteran's neurological disorder is a variant of ALS or a separate neurological disorder, the Board requested an opinion from a VHA medical expert, who rendered the requested opinion in March 2014. The VHA expert, a neurologist, stated that the two diseases differ in that PLS affects only upper neurons and has a slower clinical course, whereas ALS affects both upper and lower neurons and progresses more quickly. The VHA expert stated that neurologists would be evenly split on whether PLS is a variant of ALS or a separate neurological disorder, as the answer to this question would depend on whether the neurologist used broad or narrow categories to classify diseases. Accordingly, the VHA expert stated that whether the diseases are different clinical entities was a question of semantics, and thus concluded that it was at least as likely as not that PLS is a variant of ALS. Analysis The competent and credible evidence of record on the question of causation in support of the claim consists of the opinion of a VHA expert, a neurologist. The VHA expert expressed the opinion that it was more likely than not that PLS is a variant of ALS, and not a separate neurological disease, although acknowledging that many neurologist would categorize the two diseases as separate clinical entities. The competent and credible evidence of record against the claim consists of the opinion of a VA physician. The VA physician, an internist, stated that the Veteran does not have ALS, but rather a separate neurological disorder, PLS. In support of this opinion, the examiner noted that the diagnosis of PLS, and not ALS, had been rendered by both private and VA neurologists alike. With regard to medical opinions, the probative value or evidentiary weight to be attached to a medical opinion is within the Board's province as finder of fact. The guiding factors in evaluating the probative value of a medical opinion include whether the opinion applied valid medical analysis to the significant facts of the case in order to reach the conclusion submitted in the opinion. When, after careful consideration of the entire record, a reasonable doubt arises regarding a material issue of fact, such doubt will be resolved in favor of the Veteran. By reasonable doubt is meant one which exists because of an approximate balance of positive and negative evidence which does not satisfactorily prove or disprove the claim. Whereas here the same set of facts have resulted in contradictory conclusions, the Board finds that there is an approximate balance of positive and negative evidence, which does not satisfactorily prove or disprove the claim. As the positive and negative nexus opinions are of equal probative value, the Board finds that the evidence of record is in equipoise as to the matter of whether primary lateral sclerosis is a variant of ALS, and reasonable doubt is resolved in the Veteran's favor. 38 U.S.C.A. 5107(b). As the Veteran has had 90 days of consecutive service, and as the Veteran is diagnosed with a variant of ALS, service connection pursuant to the provisions of 38 C.F.R. 3.318 is warranted. ORDERService connection for primary lateral sclerosis, a variant of amyotrophic lateral sclerosis, is granted. Page 2 Tracy, any difference behind us. The PVA has to have the diagnostic code for PLS from your Neurologist. Even withthat from him/her don't get discouraged if the VA wants a second. The PVA can file without it but... The best route is to have a code from a civilian Neurologist and a VA Neuro. And there is... BOVA (Board of Veteran Appeals), if you have to, has been noted latelyto grant in favor of the Veteran more than previously. Mike might have more to chime in on recent BOVA cases. Hopefully not this far but... there is COVA (Court of Veteran Appeals.) Hang in there... be patient. PS. If you do file as is and it is denied do not file an Appeal right away.Advice is cheap but I'll give you mine on the other side if that happens. Don't mean to add on here. You may already know this. The other sideof filing now is (example)... you file now and it is denied, later as moreevidence comes about you file an appeal, the VA has to pay youretro-actively to the date you filed. In rare cases they will go backto the date you were diagnosed.That's why some may say "file now." Last edited: Jun 13, 2018 Thanks Clearwater!I filed an "intent to file" with ebenefits back in Dec, and if I understand it correctly they will pay retroactively back to that date. (I started it then, before realizing I might be making a mistake to file by myself.) It was also questionable in my mind at the time whether it was ethical to file, until my neurologist explained that it is often a 'genetic marker "turned on" by an environmental exposure' and I learned more about how vets are 2x more likely to develop. Still, the definitions in "gulf war illness" seem so iffy. But it seems my mobility is tanking pretty fast, and I don't know how long I'll be able to work, and the auto and home mods that would become available might be really helpful soon. So I have convinced myself to give it a whirl, and now I want it to be a solid whirl. These are all really good points you bring up, especially about the appeals, thank you for the tips! Let's hope the "Gulf War Illness" study gives supporting evidence to your claim. In the case Mike posted the Veteran apparently was/is on the Agent Orange Registryand Agent Orange has accredited links to several illnesses. I haven't followed the "Gulf War Illness" being a Viet Nam Vet... has the Gulf WarIllness study given any accredited links to any illnesses? I'm in the Agent Orange Registry. It's kind of a goofy thing and I wish they'd just change the name to "environmental exposure" database. I think they just realized that they already had a tool from Vietnam that could be used for Gulf War exposures and there way no point in creating another database. I approve & agree with that idea. But I think they should change the name because I believe it confuses a lot of vets. As far as Gulf War Illness, I don't think there really is such a thing. Instead, there are a lot of vets that came back that have an unusually high rate of a variety of symptoms, and nobody knows why. So they recognized that this is a statistical truth, and that these vets need treatment, and since nobody knows why, they threw all of these symptoms in to one bucket and called it GWI. I suspect that as time progresses and they are able to isolate different symptoms to diseases and causes, they will start to break those out. (Maybe they won't bother.) But for now, there is a label that GW vets experiencing symptoms can use to claim treatment and benefits. A set of these symptoms are "presumed service connected" if the vet was in the gulf and the symptoms are undiagnosed. There is also a set of diagnosable illnesses (like fibromyalgia and a few others) but that is a very specific list of a few things. ALS is always assumed service connected in this case. There is imo a gap that exists between "multiple undiagnosed symptoms" and these few specific diagnosed illness and ALS, and I think vets sometimes fall into that gap and get denied. I realize there's a lot of subjective observations, and certainly welcome any comments or corrections from the group. The last part of your question was about studies. Congress ordered a slew of them, not just one. Several are published, some ongoing. The findings for many of the neuro conditions have been hit and miss imo depending on which study one reads. Tracy, how were able to get on the Agent Orange Registry with your service beingfrom 1983 to 2004? As i understood the Registry it was defined to those who served in areas AgentOrange was used. If Gulf War Illness has been brought under the umbrella ofAgent Orange it might be supporting evidence. Edit... you posted above while I was composing this.You may know but you did mention Congress and the messy politics. Do not getyour Congressman/woman or any politician involved. Many times Veterans getfrustrated and call their Congressman/women. The Congressperson hears thecomplaint and hands it off to his/her aide, they call the VA, the VA has to stopand answer the aide, then another call just dragging the process even slower. I think you're aware of this... I wanted to mention it for other Veterans readingthis Thread. Last edited: Jun 15, 2018 The thought didn't occur to me to call a congressperson, I don't think I'm anywhere near that, as it sounds like you've ascertained. But I'm not sure I agree with you about the wisdom of doing so if circumstances warrant. After I retired from the service I did some time as a DoD contractor and then as a federal civilian (GS) supporting the Navy. When we got congressional queries in, you're right, I had to put other things that I thought were more important on pause to handle the query, which was very frustrating. However, those queries did get my undivided attention until they were resolved, and bet your ass the answers were well researched. I wouldn't suggest everyone call their rep out of pocket. On the other hand, if it is clear that a case was mishandled and all other resources and avenues were exhausted, I absolutely think it they should. And your point's well taken that one person's congressional query *could* (only if acted on by the congressional staffer) result in another person's claim being paused until it were answered, and too many could break the system or cause more urgent cases to be unjustly delayed. So that should be used only for cases where due diligence were exhausted and mishandling seems likely. My opinion only, based on my experience, and I never worked at the VA. Last edited: Jun 15, 2018 ...and to your point, responding to an inquiry didn't necessarily result in a favorable answer to the citizen once the research was done; calling a congressperson doesn't mean problem solved. So again, only as a last resort in a mishandled case after all due diligence is done. And a "no" or slow response from the VA doesn't necessarily equal a mishandled case. Thanks for the reply. Let's hope it doesn't get to a point you consider bringing ina politician. The best representation you can have is the PVA. As for other Veterans following this thread... how were you able to get on the Agent Orange Registry? Your experience (history - government workings) is so much more than a common Veteran filing a claim. Your thread can be and is very helpful. Ok, ok... I had to plow through several web sites and I think I have figured outwhat they have done. It's not as cut and dry as the Agent Orange Registry but...they haven't done you guys much of favor. The VA had to be water boarded withevidence before they finally gave into accredited links to certain illnesses linkedto Agent Orange. The Gulf War Vets really are just beginning. But... hopefully it will be consideredsupporting evidence to your claim and not years as it was for Viet Nam Vets. My husband was diagnosed in June with PLS. He had mild speech difficulties (slurring when tired) starting a year prior that have progressed since. He is increasingly nasal and slurred; he must speak each word slowly to be understood. He now has some toe drag with each foot and needs a cane for stability. We pray his arms and hands will be the last affected as he is a potter and his art means so much to him. My question is for those whose symptoms began with speech: how long does he likely have before his speech becomes unintelligible? I know PLS is different for everyone, but my husband had hoped to record enough of his speech to synthesize it for use when he can't talk anymore, and it seems to be declining more rapidly these last couple of months. Thank you for any insights. Sorry. I don't think there's a reliable answer.Just be sure to take care of him and don't let him get exhausted. Feed him well and give him good bed, so he can have as much strength as possible. Very sorry to hear about your husband, Anita. Do you mean PLS or ALS? Just double-checking since bulbar-onset PLS is rare. You might consider work on how he will access his computer as he progresses, e.g. switches, a virtual keyboard, head mouse, etc. and explore apps where he could still create designs that someone else could form/fire. Best,Laurie Thanks, Laurie. Yes, Michael has bulbar onset PLS, not ALS. At least as far as the neurologist at the ALS Clinic can determine at this time, based on the (relatively) slow progression he has experienced. But she said he'll have to go four or five years more without lower neuron involvement before she can definitively say it is PLS and not slow-developing ALS. I understand that bulbar onset ALS is typically one of the fastest to progress. I wondered if anyone here has had experience with bulbar onset PLS, hoping for a relative sense of how quickly he's likely to lose his speaking ability. Good idea to research creative apps that Michael could continue to use to design pottery even when he can no longer make it. He's just now beginning to work with an iPad for speech assistance. We're hoping to find something that can give him enough improvement in his speech, even temporarily, that he could successfully record enough speech to make his own voice the voice for the app. The Patients Like Me site shows that some PALS have had bulbar improvements with the use of Requip (ropinirole), a medication approved for Parkinsons disease, Anyone in this PLS group have experience with Requip? Thanks,Anita You may also want to look into Nuedexta. It seems to help bulbar symptoms for some people. I wouldn't worry too much about rushing to record what is still going to be a pretty mechanical voice. Most PALS don't get that done, and life goes on. Whether he uses an enriched voice or not, even just recording some key phrases that you can integrate into his TTS system could mean a lot. If he gets the whole quota done, it could be a slightly better voice, but there's not a huge difference and he might have other things to do. There is not a lot of data for predicting speech decline in multifocal PLS with bulbar onset, but he could certainly plateau speechwise at some point. I actually don't remember how long it took before my voice was completely gone--about three years, I think. In the morning when rested, I may be able to speak a few sentences that people who spend time with me can understand. Talking is very tiring, as it seems that I'm working to force enough air out to speak. I now have some tongue atrophy, as well as facial muscle weakness. Even though it's very frustrating to be unable to speak, it's amazing what adjustments a person can make.From the time of diagnosis, I've been unable to blow into a spirometer so getting an accurate FVC measurement is impossible. This is a constant point of contention with my doctors. I don't seem to have breathing difficulties and purchased an oximeter. Once in a while my reading drops to 91% when I have been sleeping soundly, but normally doesn't go below 93%. I was extremely ill with a non-stop cough this winter and was refused admittance to the hospital because my oxygen level was too high. I even requested an arterial blood draw which was normal. Thanks for the advice about Nuedexta, Laurie. Michael has his 3-month follow-up with the neurologist very soon, so we want to talk with her about various possible options. I also appreciate your thoughts on not putting too much emphasis on these voice databank recordings. It has created some real anxiety about timeline, and maybe it won't make all that much difference. I'd imagined it would significantly improve the sound quality, really capturing his tonal quality, but I gather that isn't really realistic, then? This voice recording more my hangup than his, I think, as Michael has always been a verbally agile person, loves wordplay and inside jokes and is very expressive. Already his voice has been robbed of almost all tonal quality and range. He can't sing at all anymore. I am quite devastated at the thought of not hearing his real voice in the future, more than most other ramifications of the disease. But you're right that recording a few key phrases may go a long way to keeping his "voice" present in our lives. re: a possible plateau, speechwise. Thanks for that note of hope. It means a lot right now. Thanks for taking the time to share. Best,Anita Thanks for sharing your experience. Michael, too, finds it hard work to force enough air out to speak. It definitely tires him. On the ModelTalker site, there is a demo link where you can generate some actual examples of what the voice bank output sounds like in a best case scenario (professional recording). I understand what you are saying about hearing Michael's voice in the future, but I can also tell you that I can hear my husband's pre-ALS voice still, 4y after his death, without any help. I would imagine there is someone in your life of whom you can say the same. Best,Laurie I have bulbar PLS. My symptoms started almost 8 years ago. I can still speak. My voice is slurred, weak and takes lots of effort, but I can still make myself understood most of the time. I think the major decline was in the first 2 years. So, a plateau is possible for your hubby. I have bulbar PLS. My symptoms started almost 8 years ago. I can still speak. My voice is slurred, weak and takes lots of effort, but I can still make myself understood most of the time. I think the major decline was in the first 2 years. So, a plateau is possible for your hubby. Thanks very much for sharing your experience. That really does give us hope. Michael's speech has worsened since his last 3-month check-in at the ALS Clinic, but it helps to know this may not continue to be a steady decline, or at the same pace. It is so strange how this disease takes a different course for almost every person. Praying for a plateau. I see you are in Vancouver, BC. Do you see Dr. Briemburg at the ALS Clinic there? Wondering what medication, if any, you are taking for your PLS symptoms (bulbar and otherwise), and what has been most useful to you. Hi Anita,Yes, I see Dr. Breimberg. I take a compounded version of nuedexta plus a small dose of Escitalopram. I find that this combo helps with pseudo-bulbar affect (PBA), and maybe a bit with speech. You might want to join the Primary Lateral Sclerosis (MND) group on Facebook. We often have some interesting discussions about equipment, strategies, etc.Regards,Lori Hi Anita,Yes, I see Dr. Breimberg. I take a compounded version of nuedexta plus a small dose of Escitalopram. I find that this combo helps with pseudo-bulbar affect (PBA), and maybe a bit with speech. You might want to join the Primary Lateral Sclerosis (MND) group on Facebook. We often have some interesting discussions about equipment, strategies, etc.Regards,Lori Thank you, Lori. Dr. Briemberg told us that the compounded version of Neudexta is no longer available because one of the ingredients used to compound it is an older no-longer-relevant drug that the manufacturer has stopped making. Are you working from a past supply, or did I somehow misunderstand Dr. B? I sure hope she is wrong, although the quinidine part of it is kind of an obscure drug. I filled my prescription in July. I'll PM the details to you.

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