



VIA ELECTRONIC DELIVERY

March 11, 2025

Robert Parks, Chief, Part 3 Regulations Staff (211C)
Compensation Service (21C)
Veterans Benefits Administration
Department of Veterans Affairs
810 Vermont Avenue NW
Washington, DC 20420

RE: AS27-Interim Final Rule-Presumptive Service Connection: Leukemias, Multiple Myelomas, Myelodysplastic Syndromes, and Myelofibrosis Due to Exposure to Fine Particulate Matter

Dear Mr. Parks:

CLL Society appreciates the opportunity to write in support of the Veterans Benefits Administration's (VBA's) Interim Final Rule establishing a presumptive service connection for Veterans who were exposed to fine particulate matter and subsequently diagnosed with leukemia, multiple myeloma, myelodysplastic syndrome or myelofibrosis. In particular, we appreciate that the VBA put Veterans first and promulgated the new regulatory provisions as an Interim Final Rule with a January 10, 2025 effective date.

CLL Society is dedicated to addressing the unmet needs of the chronic lymphocytic leukemia and small lymphocytic lymphoma (CLL/SLL) community through patient education, advocacy, support, and research. We are the largest nonprofit focused exclusively on the unmet needs of patients living with CLL and SLL.

We strive to fulfill our primary mission of ensuring that patients have access to safe and effective treatment options by informing patients and caregivers about the rapidly changing therapeutic landscape and the importance of clinical trials, supporting, and building patient networks, engaging in research, and educating providers and patients. We are particularly committed to providing veterans with the information and support they need to navigate the benefits their service entitles them to receive. For example, CLL Society provides Veterans with:

- Informational content for newly diagnosed Veterans with CLL/SLL.



- Webinar content providing perspectives from a VA physician and a Veteran with a CLL diagnosis.
- Updated “FAQs” for Veterans with CLL/SLL on applying for VA benefits and treatment options in the VA, including options for Veterans in areas where VA facilities are not available.
- Comprehensive information on applying for disability benefits from the VA.
- CLL Society support groups to connect Veterans with other Veterans diagnosed with CLL/SLL.
- Help in identifying a VA provider with CLL/SLL expertise.
- CLL Society’s Expert Access Program offering a free CLL/SLL expert consultation for patients that they can share with their local provider as they develop a treatment plan.

Background: CLL/SLL

CLL is a chronic blood cancer of a type of white blood cell called the B-lymphocyte. While rare, CLL is the most common leukemia in U.S. adults, with around 21,000 cases diagnosed annually. CLL is both a type of leukemia and a type of non-Hodgkin’s Lymphoma (NHL). We agree with the VA’s understanding that CLL and SLL are a single disease. SLL is simply a different manifestation in which there are not yet a significant number of cancer cells located in the bloodstream. When the cancer is only found in the lymph nodes it is called SLL. When the cancer is found in the bloodstream and possibly elsewhere, including lymph nodes, it’s called CLL.

CLL/SLL is extremely heterogeneous in terms of disease course and progression. Some patients have an aggressive form of the disease, generally identified by genetic expression as higher-risk, experience rapid deterioration, and survive for as little as two years. Others have a less aggressive form of the disease, may never need treatment, and can expect to have a normal life expectancy. For most patients, CLL/SLL is indolent and incurable. The goals of therapy are to improve quality of life and prolong overall survival (OS).¹ Today, the median overall survival (OS) from start of front-line therapy is 5 to 15 years, depending on disease features, individual patient factors, and treatment choices.

¹ [Selection of initial therapy for symptomatic or advanced chronic lymphocytic leukemia/small lymphocytic lymphoma - UpToDate](#)



Although CLL/SLL patients now have more treatment options compared to just years ago, most patients will experience one or more relapses during the course of their disease, and many are forced to either change treatments, take a “drug holiday,” or adjust dosing due to drug intolerance. For patients with relapsed or refractory disease (or treatment intolerance), treatment decisions are highly individualized based on prior therapies, prior response, the reason for discontinuation of previous therapy, comorbidities, biomarker characteristics, patient preference, and therapeutic goals. Patients can experience serial relapses, and many will be treated with all available agents at some point during their disease course.

In addition, patients with CLL/SLL commonly develop complications associated with immune dysfunction resulting in immunodeficiency and autoimmune disorders. The most common CLL-related complications are infection, anemia, and thrombocytopenia. Potentially life-threatening, but less common, complications include tumor lysis syndrome and second cancers.²

CLL Society fully supports VBA’s expansion of presumptive service connection for leukemias

Enactment of the Sergeant First Class Heath Robinson Honoring our Promise to Address Comprehensive Toxics Act of 2022 (the PACT Act) was a very important step toward ensuring that Veterans exposed to toxins who later developed serious medical conditions can access VA benefits, including disability benefits without the delays associated with establishing a service-to-diagnosis connection. The PACT Act specifically included CLL/SLL within the set of conditions for which a presumption of service connection applies to Vietnam War era Veterans exposed to Agent Orange or serving in specific areas where toxic exposure was likely. This presumption also applied to Veterans diagnosed with “Lymphoma of any type” who served in the “Southwest Asia theater of operations or Somalia” after August 1990 and to post-9/11 Veterans who served in Afghanistan, Djibouti, Egypt, Jordan, Lebanon, Syria, Uzbekistan, or Yemen.

As outlined above, CLL/SLL is best understood as (1) a single condition; and (2) **both** a lymphoma and a leukemia. We understand that the VBA classifies conditions within a set of categories to which codes are assigned for benefit eligibility and disability rating purposes. Unfortunately, the decision to classify CLL/SLL as a leukemia, though correct, created the technically incorrect conclusion that CLL/SLL is **not a lymphoma**. Veterans within our patient community who had served in eligible areas (for a lymphoma presumption) during the Gulf War and developed CLL/SLL



have faced a difficult, multiple-year path to establish that their cancer was connected to their service. Some Veterans have successfully obtained VBA benefits for CLL / SLL due to burn pit exposure after benefit denials and appeals. Others faced continuing denials based on a failure to show exposure to Agent Orange, as would have been (prior to this Interim Final Rule) required to fit within the presumption for a chronic leukemia. Unfortunately, the expert evidence successfully demonstrating a connection between burn pit exposure and CLL/SLL for one Veteran could not be used to establish such a connection for another Veteran regardless of the similarities between their exposure and condition.

CLL Society appreciates the significant efforts required to review evidence and move through the processes outlined in the PACT Act to establish a service connection presumption for the conditions discussed within the Interim Final Rule. We agree with VBA's conclusions and urge the Administration to maintain its determinations and ensure that:

- **Both** CLL and SLL are clearly included as diseases to which the service connection presumption for leukemias applies. We are concerned that Veterans and their providers may remain confused and misinterpret the Administration's actions as applying only to CLL with SLL remaining excluded from the set of eligible lymphomas.
- Determinations on disability ratings and reviews (e.g., 100% disability rating for "active disease" or "during treatment stage" are informed by the nature of CLL/SLL and its treatments, including the potential for patients to stay on a treatment until disease progression and to suffer long-term sequelae from their CLL/SLL or their treatment.

Conclusion

Once again, we appreciate the opportunity to contribute the perspectives of our CLL/SLL Veteran communities. If you have any questions, please feel free to contact me or Saira Sultan, CLL Society's Healthcare Advocacy & Policy Consultant, via email at saira.sultan@connect4strategies.com.

Sincerely,

Carly Harrington
Executive Director, CLL Society