[Name of your Representative or Senator] [Date]

My name is [Insert name], and I am a constituent of yours, living in [Insert town and state].

I am writing to you regarding the Restless Legs Syndrome Foundation (RLSF), which advocates for all persons affected by RLS and supports a legislative and policy agenda that meets the needs of the RLS community. The foundation’s mission is to improve the lives of men, women, and children who live with RLS, working to raise awareness, improve treatments, and—through research—to find a cure for this often-devastating disease.

RLS is a neurological disorder that causes sensory disturbances and an urgent need to move the legs and/or, in some cases, other parts of the body, such as the arms. Patients describe the feelings in a variety of ways, which can range from relatively mild to severe, from only rarely experienced to an intense daily torture. RLS can have profoundly disruptive effects on the quality and quantity of sleep and on virtually every other aspect of daily life as well. Currently in the United States, it is estimated that nearly 12 million adults and children suffer from RLS. I am one of them. [or substitute an appropriate sentence connecting you to your advocacy efforts for RLS.]

[Tell your own story about RLS—ideally in a paragraph or two.]

I am writing today to ask for your help in supporting several measures that will benefit the RLS community. There is currently no cure for RLS, and treatment options are limited. Research remains critical to improving the health and quality of life of individuals suffering from this disease. We advocate a funding level of $46.1 billion for the NIH in the FY 2022 Labor-HHS-Education Appropriations bill. This level of funding will support the progress that the NIH has made in medical research regarding RLS and other chronic diseases.

Over the past decade, “sleep disorders” has been listed as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP). Please work with your colleagues to ensure that “sleep disorders” is listed once again in the FY 2022 Defense Appropriations Bill. The RLSF, as part of the sleep research community, asks that your office contact your colleagues on the Defense Appropriations Subcommittee to communicate your support for this request.

In cases of severe RLS in which all other medical therapies have failed, ample scientific research supports the use of low-total-daily-dose opioid therapy to treat the underlying neuropathology associated with RLS, which is **not** the same as chronic pain. Research continues to show that addiction and dependence are not common complications for affected individuals, because the total daily dose of opioids used to manage RLS is quite low, and patients continue on the same total daily dosage for years and even decades. However, the low-total-daily-dose opioid medications must be kept at the same level to manage symptoms. If patients with severe RLS lose access to opioid therapies, they suffer extreme loss of sleep, continuous misery, and worse. The needs of RLS patients who depend on the use of low-total-daily doses of opioids to manage their disease must be considered in crafting legislation, policies, and regulations aimed at drug abuse and addiction. Please work with your colleagues in Congress to ensure that RLS patients retain access to physician-directed care and treatment for severe cases of RLS.

Poor provider education about Restless Legs Syndrome routinely leads to misdiagnosis, delays, and inappropriate treatment, which often results in irreparable harm to patients. Improved provider education can drastically improve effective treatment outcomes. The CDC’s National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) supports several programs that work to increase public awareness and improve professional education for chronic diseases such as RLS. Please provide $5 million for the National Neurological Conditions Surveillance System (NNCSS) and $5 million for the Chronic Diseases Education and Awareness Program (CDEA). Through a competitive grant process, the new CDEA program will greatly enhance understanding, education, and public health awareness for a variety of chronic diseases, including RLS.

Thank you for your consideration of these vital issues, and please consider the RLS Foundation as a resource for you and your office about health-related and patient issues.

Sincerely,

[Your name

Your street address

Your city and State]