Good afternoon Senators, Thank you for the opportunity to present support of Bill 2007, An Act to Create the Amyotrophic Lateral Sclerosis Incidence Registry. My Name is David Doane and I live in Bucksport Maine, and I am a person (pALS) with Amyotrophic Lateral Sclerosis (ALS). ALS is a rare, fatal disease, the incidence of ALS is approximately two per One Hundred Thousand, there is no cure and only 2 approved medications that can slow disease progression in some pALS for only a few months. Almost 50% of those diagnosed with ALS die in the first 2 years after diagnosis with 90% dying by the fifth year. ALS is a cruel, insidious disease, talking away your ability to walk, talk eat and breathe. About 10% of cases are familial (genetic) with the remaining cases the origin is undetermined (sporadic). Veterans are three times more likely to be stricken with ALS and Gulf War veterans have been reported to be TEN times more likely to be stricken with this fatal disease. All cases of ALS are different, some impacting a patient's ability to eat and speak (bulbar) at first, while others are impacted by limited use of hands and, or feet (limb onset) and all pALS progression is at different rates. **ALS is always FATAL.**

I am here today in support of this bill to make sure every Mainer stricken with this deadly disease is counted, and that the appropriate funds, therapies and services are provided to those living in Maine. There is a national registry, however there is no required reporting by healthcare providers, and it is by self-reporting by pALS only! I believe that those living with Maine is under reported significantly. Just think for a minute, if you are told you have 2-5 years to live, start getting your affairs in order where does enrolling in the registry fall on your priority list? Most likely at bottom, so why is this registry important?

1. To provide correct counting of ALS patients in Maine, to assure that services, technology and maybe therapies that could improve and extend the life of ALS patients. Maine has a small

multidisciplinary clinic in Brunswick, unfortunately it does not provide Mainers with access to new technologies, research, clinical trials and Expanded access programs. To obtain these services you must travel to Boston, an option not possible for many ALS patients due to disease progression and physical limitations. Correct reporting of pALS should assure appropriate services are provided.

2. To provide valuable research data to help identify “clusters”, clusters are areas of higher-than-normal incidence that may be due to environmental contact.
3. This Act does not burden healthcare providers with significant additional cost or expense, yet its product yields valuable data.
4. Since the population of Maine is aged it is anticipated the incidence of ALS will increase as does the average age of the Maine’s population.
5. Create and maintain additional awareness of ALS

I am one of the luckier pALS, in that my progression is slow and I have the ability to access services and therapies from the greatest ALS center in the world (Mass General). But because of my relatively strong health and am currently living without a tracheostomy, a respirator, feeding tube it is my responsibility to speak out for those who cannot. Please provide all ALS patients the opportunity for hope by supporting An Act to Create the Amyotrophic Lateral Sclerosis Incidence Registry.

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