



For Immediate Release
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STRAUS ANNOUNCES SPONSORSHIP OF AMENDMENT ON LOU GEHRIG'S DISEASE

Boston: Rep. Bill Straus (D-Mattapoisett) announced today that he is the lead sponsor of a House Budget Amendment which would direct the State to fund the ALS (Lou Gehrig's Disease) Registry. The Registry was created in the Fiscal Year 2004 Budget, but funding was not provided.

ALS is a fatal neuromuscular disease characterized by progressive muscle weakness resulting in paralysis. There is no cure, and 50 percent of all ALS patients die within 18 month of being diagnosed.

"The State has an obligation to make sure it is doing all it can to fight this terrible, devastating disease, and the key element in this fight is to establish an accurate number of those affected," stated Straus.

This Registry will help the State detect the actual incidence of ALS, possible changes in incidence and possible ALS clusters throughout the State. This information is vital as federal funding is directly tied to the number of patients affected.

"The fundamental reason of this Registry is to get an accurate count of those who have ALS because the old number of 5,000 per year is antiquated and is negatively effecting the allocation of federal resources used to fight this terrible disease," stated Dick Douglas a Fairhaven resident whose son has ALS.

There is suspicion that the actual incidence of ALS is equal to those of Muscular Dystrophy or Cystic Fibrosis. However, the reason this number is so hard to ascertain is because those afflicted with ALS die so quickly, leading to lower numbers in the population.

The House budget debate begins on April 26, 2004, and will then proceed to the Senate for further consideration.

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