

SIXTEENTH CONGRESS OF THE REPUBLIC OF THE PHILIPPINES Second Regular Session

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SENATE P.S. Res <u>**865**</u>

RECEIVED BY

Introduced by Senator Poe

RESOLUTION

URGING THE DEPARTMENT OF HEALTH, UNIVERSITY OF THE PHILIPPINES-PHILIPPINE GENERAL HOSPITAL (UP-PGH) AND OTHER STATE ACADEMIC INSTITUTIONS AND HOSPITALS TO CREATE A STUDY ON AMYOTROPHIC LATERAL **SCLEROSIS** GROUP (ALS), **NEURODEGENERATIVE DISEASE THAT AFFECTS NERVE CELLS IN THE** THE SPINAL CORD LEADING BRAIN AND TO PARALYSIS, TO DETERMINE THE EXTENT OF ITS AFFLICTION AND THE NUMBER OF AFFECTED FILIPINOS, WITH THE INTENTION OF PROVIDING SUPPORT **MECHANISMS** ASSISTANCE PATIENTS AND TO AND RAISING AWARENESS ABOUT THE RARE DISEASE

Whereas, Amyotrophic Lateral Sclerosis (ALS), also referred to as Charcot Disease, Motor Neurone Disease, and, in the United States, Lou Gehrig's Disease,¹ was first found by French neurologist and anatomical pathology professor Jean-Martin Charcot in 1869, but it wasn't until 1939 that Lou Gehrig—dubbed the Iron Horse of Baseball—brought international attention to the disease when he abruptly retired from baseball after being diagnosed with ALS²;

Whereas, the fatal and progressive neurodegenerative disease affects nerve cells in the brain and the spinal cord. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, patients in the later stages of the disease may become totally paralyzed³;

Whereas, the cause of ALS is not yet known and the disease has no known cure, although medications are available to help patients reduce fatigue, pain and depression, among others;

Whereas, in 1995, the US Food and Drug Administration approved the use of rilozule to reduce damage to motor neurons and prolong patient's survival, but does not repair damaged motor neurons;

Whereas, three classifications of ALS are identified in the US: Sporadic, Familial and Guamanian. Sporadic is the most common form in the US that affects 90 to 95 percent and may affect anyone, anywhere. Familial, which is hereditary, occurs in 5 to 10

¹ http://en.wikipedia.org/wiki/Amyotrophic_lateral_sclerosis

² http://www.alsa.org/about-als/

³ http://www.alsa.org/about-als/what-is-als.html

percent of all cases, while Guamanian was identified in Guam and the Trust Territories of the Pacific in the 1950s⁴;

Whereas, in the US, more than 12,000 people were diagnosed with ALS as of 2011, for a prevalence of 3.9 cases per 100,000 persons in the US general population, according to the US Centers for Disease Control and Prevention⁵;

Whereas, a viral fundraiser is making the rounds over social media dubbed the Ice Bucket Challenge where people douse ice water over their heads and donate money to ALS Association for research. The ALS Association has so far raised \$79.7 million from 1.7 million donors around the world as of August 25, 2014⁶, compared with \$2.5 million during the same period in 2013. The organization raised \$64 million in 2013;

Whereas, in the Philippines, the Department of Health (DoH) does not have data on prevalence of ALS in the country while formal support groups are also lacking;

Whereas, the DoH, in partnership with foreign research and medical institutions with advanced research on ALS and state hospitals and educational institutions with specialty in medicine could create a support group to provide assistance and specialized ALS care and services to Filipinos afflicted with ALS and raise public awareness of the disease;

RESOLVED, as it is hereby resolved, by the Senate of the Philippines, that the Department of Health, University of the Philippines-Philippine General Hospital (UP-PGH) and other state academic institutions and hospitals be urged to create a study group on Amyotrophic Lateral Sclerosis (ALS), a neurodegenerative disease that affects nerve cells in the brain and the spinal cord leading to paralysis, to determine the extent of its affliction and the number of affected Filipinos, with the intention of providing support mechanisms and assistance to patients and raising awareness about the rare disease.

Adopted,

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GRACE POE

⁴ http://www.alsa.org/about-als/forms-of-als.html

⁵ http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6307a1.htm

⁶ http://time.com/3173833/als-ice-bucket-challenge-fundraising-total/