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THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 557 Session of 2000

INTRODUCED BY ARGALL, ARMSTRONG, BAKER, BARD, BEBKO-JONES, BELARDI, BENNINGHOFF, CALTAGIRONE, CAPPABIANCA, CLARK, CLYMER, L. I. COHEN, M. COHEN, CORRIGAN, COSTA, COY, DALEY, DeLUCA, DERMODY, DeWEESE, DONATUCCI, FAIRCHILD, FARGO, FICHTER, FLEAGLE, FORCIER, FRANKEL, FREEMAN, GEIST, GEORGE, GRUCELA, HALUSKA, HARHAI, HASAY, HERMAN, HERSHEY, HESS, HORSEY, JOSEPHS, KENNEY, LAUGHLIN, LEDERER, LEH, LESCOVITZ, LUCYK, MAITLAND, MAJOR, MANDERINO, MANN, MARSICO, MASLAND, McCALL, McNAUGHTON, MELIO, R. MILLER, S. MILLER, MUNDY, NAILOR, ORIE, PESCI, PIPPY, PISTELLA, RAMOS, READSHAW, ROSS, RUBLEY, SANTONI, SATHER, SAYLOR, SCHRODER, SCHULER, SCRIMENTI, SHANER, B. SMITH, SOLOBAY, STABACK, TANGRETTI, E. Z. TAYLOR, THOMAS, TIGUE, TRAVAGLIO, TRUE, WASHINGTON, WATERS, WILLIAMS, WILT, WOJNAROSKI, YOUNGBLOOD, ZIMMERMAN AND ZUG, JULY 31, 2000

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, JULY 31, 2000

A RESOLUTION

Recognizing the week of November 26 through December 2, 2000, as "Spinal Muscular Atrophy Week" in Pennsylvania.

WHEREAS, Spinal muscular atrophy is the number one genetic killer of children under two years of age, and one in 6,000 babies born each year is affected by spinal muscular atrophy; and

WHEREAS, Of infants diagnosed with spinal muscular atrophy, 50% will die before their second birthday; and

WHEREAS, Spinal muscular atrophy is an autosomal recessive disease where a child of two carriers has a one in four chance of developing the disease, and approximately one in every 40

people carries the deadly gene that causes spinal muscular atrophy; and

WHEREAS, Spinal muscular atrophy is a disease of the anterior horn cells which destroys the nerves in the spinal cord that control voluntary muscle movement, affecting crawling, walking and even swallowing; and

WHEREAS, Spinal muscular atrophy does not discriminate on the basis of race or gender; and

WHEREAS, Type I (acute) spinal muscular atrophy, also called Werdnig-Hoffmann disease, is usually diagnosed before three months of age and is characterized by a difficulty lifting the head, a general weakness in the intercostals and accessory respiratory muscles and a concave chest; and

WHEREAS, Type II (chronic) spinal muscular atrophy is usually diagnosed before two years of age and is characterized by a difficulty coming to a sitting position without assistance or a difficulty standing alone without aid; and

WHEREAS, Type III (mild) spinal muscular atrophy, also referred to as Kugelberg-Welander syndrome or juvenile spinal muscular atrophy, is often recognized after 18 months of age and is characterized by a difficulty with walking or getting up from a sitting or bent position; and

WHEREAS, Type IV (adult onset) spinal muscular atrophy is often diagnosed after 35 years of age and is characterized by problems with the bulbar muscles used for swallowing and respiratory function; and

WHEREAS, Adult onset X-linked spinal muscular atrophy, also known as Kennedy's syndrome or bulbo-spinal muscular atrophy, occurs only in males and is characterized by a noticeable breast enlargement known as gynecomastia and also affects facial and

tongue muscles; and

WHEREAS, Spinal muscular atrophy can be diagnosed by three major lab tests such as a serum enzyme test, an electromyography (EMG) test and a muscle biopsy test; and

WHEREAS, There is currently no drug, therapy or surgery to cure spinal muscular atrophy and caregivers can only treat symptoms by using reaching games, seeking the assistance of a physical and/or respiratory therapist and making the patient as comfortable as possible; and

WHEREAS, Research of the Indiana University Roster, funded by Families of Spinal Muscular Atrophy, has found one of the key families in the gene location, which will help foster additional research and studies which may one day contribute to finding a cure for spinal muscular atrophy; therefore be it

RESOLVED, That the House of Representatives recognize the week of November 26 through December 2, 2000, as "Spinal Muscular Atrophy Week" in Pennsylvania and urge all citizens to recognize the existence and severity of this disease.