THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 620

Session of 2017

INTRODUCED BY BERNSTINE, KINSEY, READSHAW, NEILSON, BAKER, DRISCOLL, RYAN, BIZZARRO, HENNESSEY, TOOHIL, LONGIETTI, CHARLTON, DUSH, SONNEY, O'NEILL, MILLARD, PICKETT, MURT, DIGIROLAMO, BOBACK, MUSTIO, V. BROWN, MARSICO, VITALI, BRADFORD, CONKLIN, WARD, D. COSTA, GILLEN, WATSON AND JOZWIAK, NOVEMBER 27, 2017

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, NOVEMBER 27, 2017

A RESOLUTION

- 1 Raising awareness of spinal muscular atrophy in Pennsylvania.
- 2 WHEREAS, Spinal muscular atrophy (SMA) is a rare genetically
- 3 inherited disease affecting the part of the nervous system that
- 4 controls voluntary muscle movement; and
- 5 WHEREAS, SMA is the leading genetic cause of death for
- 6 infants and toddlers, affecting one in every 11,000 births in
- 7 the United States; and
- 8 WHEREAS, One in every 50 Americans is a genetic carrier of
- 9 SMA; and
- 10 WHEREAS, There are an estimated 237,083 SMA carriers in
- 11 Pennsylvania; and
- 12 WHEREAS, An estimated 13 babies are born with SMA annually in
- 13 Pennsylvania; and
- 14 WHEREAS, Among autosomal recessive disorders, SMA is the most
- 15 common fatal disease and is second in birth prevalence only to

- 1 cystic fibrosis; and
- 2 WHEREAS, Symptoms in the mildest cases of SMA include muscle
- 3 weakness, muscle twitching and lack of muscle tone; and
- 4 WHEREAS, In the most severe cases, this rare disorder can
- 5 interfere with one's ability to sit unsupported and cause
- 6 difficulty breathing and swallowing; and
- 7 WHEREAS, Early detection is vital to preventing SMA from
- 8 progressing and interfering with one's basic life functions; and
- 9 WHEREAS, Significant clinical history and natural history
- 10 indicate that early treatment is necessary to provide the best
- 11 outcomes for those affected by SMA; and
- 12 WHEREAS, In addition to therapies that manage symptoms of SMA
- 13 among children and adults, the Food and Drug Administration has
- 14 recently approved the first SMA treatment; and
- WHEREAS, Improving the length and quality of life for people
- 16 with SMA starts with awareness; therefore be it
- 17 RESOLVED, That the House of Representatives raise awareness
- 18 of spinal muscular atrophy in Pennsylvania; and be it further
- 19 RESOLVED, That the House of Representatives urge the
- 20 Department of Health to analyze whether it is appropriate to add
- 21 SMA to the newborn screening list.