## THE GENERAL ASSEMBLY OF PENNSYLVANIA

## HOUSE RESOLUTION

No. 917

Session of 2018

INTRODUCED BY MURT, BIZZARRO, CALTAGIRONE, CHARLTON, DiGIROLAMO, DONATUCCI, HEFFLEY, HENNESSEY, HILL-EVANS, KINSEY, LONGIETTI, MILLARD, NEILSON, M. QUINN, READSHAW, RYAN, SAYLOR AND TOOHIL, MAY 17, 2018

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, MAY 17, 2018

## A RESOLUTION

- Designating the month of May 2018 as "SPG47 Awareness Month" in Pennsylvania.
- 3 WHEREAS, SPG47, also known as hereditary spastic paraplegia,
- 4 type 47, is an ultra-rare neurodegenerative disease, with only
- 5 20 confirmed cases worldwide; and
- 6 WHEREAS, There is no known cure for SPG47; and
- WHEREAS, The disease is caused by a mutation of the AP4B1
- 8 gene, which does not allow a child to produce a protein required
- 9 for the proper functioning of the central motor neurons in the
- 10 brain, delaying and eventually disabling the ability to walk;
- 11 and
- 12 WHEREAS, SPG47 affects two children in the United States, one
- 13 of whom resides in this Commonwealth; and
- 14 WHEREAS, More research is needed in order to create a
- 15 treatment and discover a cure; therefore be it
- 16 RESOLVED, That the House of Representatives designate the

- 1 month of May 2018 as "SPG47 Awareness Month" in Pennsylvania;
- 2 and be it further
- 3 RESOLVED, That by bringing awareness to SPG47, those affected
- 4 will feel supported by this Commonwealth through the search for
- 5 a treatment and a cure.