

A RESOLUTION

1 Designating the month of May 2018 as "SPG47 Awareness Month" in
2 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

7 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
17 month of May 2018 as "SPG47 Awareness Month" in Pennsylvania;

1 and be it further

2 RESOLVED, That by bringing awareness to SPG47, those affected
3 will feel supported by this Commonwealth through the search for
4 a treatment and a cure.