

THE GENERAL ASSEMBLY OF PENNSYLVANIA

# HOUSE RESOLUTION

No. 784 Session of  
2012

INTRODUCED BY DEAN, HENNESSEY, CALTAGIRONE, WATERS, GEORGE,  
KIRKLAND, JAMES, MICOZZIE, LONGIETTI, SONNEY, GINGRICH,  
NEILSON, YOUNGBLOOD, STABACK, D. COSTA, ROSS, BRADFORD, MANN,  
O'NEILL, GOODMAN, V. BROWN, FABRIZIO, SCHMOTZER, KULA,  
WILLIAMS, READSHAW, HESS, DONATUCCI, STERN, GEIST, DeLUCA,  
M. O'BRIEN, SCAVELLO, KORTZ, MILLARD AND DIGIROLAMO,  
JUNE 18, 2012

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, JUNE  
18, 2012

## A RESOLUTION

1 Designating April 15, 2012, as "Familial Dysautonomia Awareness  
2 Day" in Pennsylvania.

3 WHEREAS, Familial dysautonomia, also known as FD and Riley-  
4 Day syndrome, is a rare genetic disease that affects the  
5 autonomic and sensory nervous systems of children from birth;  
6 and

7 WHEREAS, It is estimated that one in 27 individuals of  
8 Eastern European and Jewish ancestry is a carrier of the gene  
9 for familial dysautonomia; and

10 WHEREAS, The most striking symptoms of familial dysautonomia  
11 are reduced sensitivity to pain and temperature and the  
12 inability to produce tears; and

13 WHEREAS, It affects every major system of the body, causing  
14 severe respiratory, cardiac, orthopedic, digestive, renal and  
15 vision problems; and

1 WHEREAS, Children with familial dysautonomia lack the most  
2 basic reflexes and instincts, resulting in an inability for  
3 their bodies to function normally; and

4 WHEREAS, Children affected by familial dysautonomia cannot  
5 control their blood pressure or heart rate, they lack the  
6 ability to suck at birth and the ability to swallow properly and  
7 are at a greater risk of developing pneumonia; and

8 WHEREAS, Familial dysautonomia was once thought to be a fatal  
9 childhood disease with most patients expected to live to only  
10 five years of age; and

11 WHEREAS, Advances in treatment have dramatically extended  
12 life expectancy, but children with familial dysautonomia still  
13 suffer from chronic and often debilitating symptoms that prevent  
14 them from leading normal lives; and

15 WHEREAS, The average lifespan of the familial dysautonomia  
16 population is approximately 15 years of age; and

17 WHEREAS, The major causes of death are the result of  
18 pulmonary complications or sudden death due to autonomic  
19 instability; and

20 WHEREAS, Due to medical advances, it is projected that babies  
21 born with familial dysautonomia within the last five years will  
22 have a 50% chance of surviving to 40 years of age; and

23 WHEREAS, There is no cure for familial dysautonomia, but  
24 treatments are supportive and preventative; and

25 WHEREAS, Supportive therapies for familial dysautonomia  
26 include medications to maintain and regulate cardiovascular,  
27 respiratory and gastrointestinal function and surgical  
28 interventions that include fundoplication, gastrostomy, spinal  
29 fusion and tear duct cauterly; and

30 WHEREAS, General population genetic screening is now

1 available, and such screening can significantly reduce the  
2 frequency of new cases of familial dysautonomia; and

3 WHEREAS, It is imperative that there be greater public  
4 awareness of this serious health issue, and more must be done to  
5 increase activity at the national, state and local levels to  
6 promote screening and to support the patients as well as their  
7 families; therefore be it

8 RESOLVED, That the House of Representatives designate April  
9 15, 2012, as "Familial Dysautonomia Awareness Day" in  
10 Pennsylvania.