

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 125 Session of
2011

INTRODUCED BY SHAPIRO, MARCH 14, 2011

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, MARCH
14, 2011

A RESOLUTION

1 Designating April 10, 2011, 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

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

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

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

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

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

14 WHEREAS, The major causes of death are the result of
15 pulmonary complications or sudden death due to autonomic
16 instability; and

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

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

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

27 WHEREAS, General population genetic screening is now
28 available, and such screening can significantly reduce the
29 frequency of new cases of familial dysautonomia; and

30 WHEREAS, It is imperative that there be greater public

1 awareness of this serious health issue, and more must be done to
2 increase activity at the national, state and local levels to
3 promote screening and to support the patients as well as their
4 families; therefore be it

5 RESOLVED, That the House of Representatives designate April
6 10, 2011, as "Familial Dysautonomia Awareness Day" in
7 Pennsylvania.