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House of Representatives  
COMMONWEALTH OF PENNSYLVANIA  
HARRISBURG

COMMITTEES

FINANCE  
HUMAN SERVICES  
POLICY  
URBAN AFFAIRS

MEMORANDUM

**TO:** All Members of the House of Representatives

**FROM:** Representative Madeleine Dean *MDA*

**DATE:** June 5, 2012

**SUBJECT:** Co-sponsorship Memo -- "Familial Dysautonomia Awareness Day" in Pennsylvania

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In the near future, I plan to introduce a resolution to retroactively recognize April 15, 2012, as "Familial Dysautonomia Awareness Day" in Pennsylvania. Also known as FD and Riley-Day syndrome, this is a rare genetic disease that affects the autonomic and sensory nervous systems of children from birth.

Children with familial dysautonomia lack basic reflexes and instincts, and cannot control their blood pressure or heart rate. The disease affects every major organ of their body. Death is primarily the result of pulmonary complications or sudden death due to autonomic instability. The life expectancy of children born with this disease, until recently, was five years of age. Due to medical advances, children born with familial dysautonomia within the last five years will have a 50 % chance of surviving to 40 years of age. However, they will still suffer from chronic and often debilitating symptoms that prevent them from leading normal lives.

Like my predecessor, Representative Josh Shapiro, and others before him, I am introducing this resolution to bring awareness to the seriousness of this health issue and to increase activity at the national, state, and local levels to promote screening and support the patients as well as their families.

If you would like to join me as a co-sponsor of this important initiative, please call Deborah Brady in my office at 783-1792.

Thank you.

## 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

16 WHEREAS, Children with familial dysautonomia lack the most  
17 basic reflexes and instincts, resulting in an inability for

1 their bodies to function normally; and

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

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

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

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

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

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

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

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

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

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

6       RESOLVED, That the House of Representatives designate April  
7 15, 2012, as "Familial Dysautonomia Awareness Day" in  
8 Pennsylvania.