
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 86

Session of
2005

INTRODUCED BY GREENLEAF, BRIGHTBILL, O'PAKE, COSTA, THOMPSON,
LAVALLE, STOUT, BOSCOLA, ARMSTRONG, CONTI, EARLL, MUSTO,
KITCHEN, FERLO, TARTAGLIONE, ERICKSON, LEMMOND, RAFFERTY,
PIPPY, SCARNATI, ORIE, STACK, TOMLINSON AND KASUNIC,
APRIL 19, 2005

INTRODUCED AND ADOPTED, APRIL 19, 2005

A RESOLUTION

1 Designating the month of May 2005 as "Tuberous Sclerosis Complex
2 Awareness Month" in Pennsylvania.

3 WHEREAS, Tuberous sclerosis, also known as tuberous sclerosis
4 complex, is a rare genetic disorder that causes tumor growth in
5 vital organs such as the brain, kidneys, heart, eyes, lungs and
6 skin; and

7 WHEREAS, Tuberous sclerosis commonly affects the central
8 nervous system and results in a combination of symptoms
9 including seizures, developmental delay, behavioral problems,
10 skin abnormalities and kidney disease; and

11 WHEREAS, The name tuberous sclerosis comes from the
12 characteristic tuber or rootlike growths in the brain which
13 calcify with age and become hard or sclerotic; and

14 WHEREAS, This genetic disorder, once known as Bourneville's
15 disease, was first identified by a French physician more than
16 100 years ago; and

1 WHEREAS, The Tuberous Sclerosis Alliance estimates that
2 50,000 Americans and 1 million individuals worldwide have
3 tuberous sclerosis; and

4 WHEREAS, Approximately one in 6,000 infants is born with
5 tuberous sclerosis; and

6 WHEREAS, Tuberous sclerosis occurs in both genders and in all
7 races and ethnic groups; and

8 WHEREAS, Tuberous sclerosis is caused by a genetic mutation,
9 either inherited or spontaneous; and

10 WHEREAS, Children who have a parent with the gene stand a 50%
11 chance of inheriting the disease; and

12 WHEREAS, Two-thirds of the cases of tuberous sclerosis are
13 believed to be a result of spontaneous mutation, having no prior
14 family history; and

15 WHEREAS, Tuberous sclerosis is the largest known genetic
16 cause of epilepsy and the second largest identifiable genetic
17 cause of autism; and

18 WHEREAS, Tuberous sclerosis frequently goes undiagnosed
19 because of the obscurity of the disorder and the mild form that
20 the symptoms may take; and

21 WHEREAS, The first clue to recognizing tuberous sclerosis is
22 the presence of seizures or varying degrees of developmental
23 delay; and

24 WHEREAS, Diagnosis of the disorder takes an average of 90
25 days, with consultation of at least three specialists, and is
26 based on a careful clinical examination combined with a brain
27 MRI scan or CT scan, renal ultrasound, echocardiogram,
28 electrocardiogram, eye exam and a Wood's lamp evaluation of the
29 skin; and

30 WHEREAS, There is currently no cure for tuberous sclerosis,

1 although treatment is available for a number of the symptoms;
2 and

3 WHEREAS, The National Institute of Neurological Disorders and
4 Stroke is studying this disorder, which may one day lead to new
5 avenues of treatment, methods of prevention and ultimately a
6 cure; and

7 WHEREAS, The only national voluntary health agency, Tuberous
8 Sclerosis Alliance, is dedicated to finding a cure for tuberous
9 sclerosis while improving the quality of life of persons
10 affected by this disease; and

11 WHEREAS, Early detection has the potential to reduce
12 developmental delay; and

13 WHEREAS, Greater public awareness and education about
14 tuberous sclerosis is necessary to ensure early detection of and
15 proper treatment for this genetic disorder; therefore be it

16 RESOLVED, That the Senate designate the month of May 2005 as
17 "Tuberous Sclerosis Complex Awareness Month" in Pennsylvania and
18 urge all Pennsylvanians to learn about this disease.