

#### HOUSE HEALTH COMMITTEE

VOTING MEETING
Wednesday, May 14th, 2025
8:45am
Irvis Office Building Room G-50
Harrisburg, PA

- 1. Call to Order
- 2. Attendance

<u>HB704 PN1437 – (Mullins)</u> An Act establishing the Neurodegenerative Disease Research Program and the Neurodegenerative Disease Research Program Fund; and imposing duties on the Department of Health. An Act establishing the Neurodegenerative Disease Research Program and the Neurodegenerative Disease Research Program Fund; and imposing duties on the Department of Health.

Amendment 00684 - (Rossi) Narrows who is eligible for grants and changes reporting requirements.

<u>HR229 PN1617 – (Hanbidge)</u> A Resolution recognizing September 19, 2025, as "Aortic Disease Awareness Day" in Pennsylvania.

<u>HR232 PN1672 – (McAndrew)</u> A Resolution recognizing May 15, 2025, through June 15, 2025, as "Tourette Syndrome Awareness Month" in Pennsylvania to raise public awareness, promote acceptance and support individuals living with Tourette syndrome and related disorders.

- 3. Any other business that may come before the committee.
- 4. Adjournment

## HOUSE OF REPRESENTATIVES DEMOCRATIC COMMITTEE BILL ANALYSIS

Bill No:

HB0704 PN1437

Prepared By:

Erika Fricke (412) 422-1774

Committee: Sponsor:

Health

Mullins, Kyle

**Executive Director:** 

Erika Fricke

Date:

5/12/2025

## A. Brief Concept

Provides for grants for neurodegenerative disease research.

## C. Analysis of the Bill

House Bill 704 creates the Neurodegenerative Disease Research Program within the Department of Health (the department). The program will fund research and infrastructure for research on neurodegenerative diseases.

## Program Administration

Department of Health is responsible for setting application requirements and deadlines, and posting the application on-line. Application requirements include proof of Institutional Review Board approval and peer review, as required. The Department must review and disburse grants, and administer the program.

Grant recipients must report on progress toward goals, major discoveries, and any other needed information within three months after the end of the grant period.

## **Eligibility**

Universities and academic research centers that conduct research on neurodegenerative diseases are eligible to be grant recipients if they received funding from the National Institute of Health within the last four years, with funds divided between eligible organizations.

## Research Program Fund

The Neurodegenerative Disease Research Program Fund is established with the State Treasury. It includes any state appropriated money, as well as any funds from the federal government, donations, grants, gifts or other funding sources. All of the money must be allocated to the Department of Health for the grant program.

## Accountability

Once a research project is completed, the department will conduct a performance evaluation.

#### Reports

The department must issue annual reports about program operations and funding starting in late summer (September) of 2025.

#### Reports must contain:

- Number of applicants
- Amount each applicant received
- Number of, and reason for, rejected applications
- Funds remaining
- Anything else the department considers important.

## Reports will go to:

- Governor
- · President pro tempore of the Senate
- Speaker of the House
- · Minority Leader of the Sente
- · Minority Leader of the House
- Chair and minority chair of appropriations of the Senate
- Chair and Minority Chair of the House of Representatives.

The report must also be posted on the department's website.

The department must create necessary rules or regulations to create the grant program.

#### **Effective Date:**

**Immediately** 

## G. Relevant Existing Laws

No program exists currently to fund neurodegenerative disease research

## E. Prior Session (Previous Bill Numbers & House/Senate Votes)

N/A

This document is a summary of proposed legislation and is prepared only as general information for use by the Democratic Members and Staff of the Pennsylvania House of Representatives. The document does not represent the legislative intent of the Pennsylvania House of Representatives and may not be utilized as such.

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## THE GENERAL ASSEMBLY OF PENNSYLVANIA

# **HOUSE BILL**

Session of 2025

INTRODUCED BY MULLINS, CUTLER, SCHLOSSBERG, NEILSON, McNEILL, KHAN, FLICK, JAMES, GIRAL, SANCHEZ, PIELLI, HANBIDGE, HILL-EVANS, CIRESI, MENTZER, HOWARD, DONAHUE, BRENNAN, McANDREW, FREEMAN, PICKETT, DELLOSO, TWARDZIK, O'MARA, FLEMING, DEASY, CERRATO, GREEN, GILLEN, POWELL, WAXMAN, PROKOPIAK, T. DAVIS, PASHINSKI, WEBSTER, STEELE, CEPEDA-FREYTIZ, MAYES, MALAGARI, SHUSTERMAN, BOROWSKI, OLSOMMER, INGLIS, KENYATTA, BURGOS, GAYDOS, SCHMITT, STAATS, MERSKI, DOUGHERTY AND WARREN, APRIL 22, 2025

REFERRED TO COMMITTEE ON HEALTH, APRIL 22, 2025

#### AN ACT

- Establishing the Neurodegenerative Disease Research Program and
  - the Neurodegenerative Disease Research Program Fund; and
- 2 imposing duties on the Department of Health.
- The General Assembly of the Commonwealth of Pennsylvania
- hereby enacts as follows:
- Section 1. Short title.
- This act shall be known and may be cited as the 7
- Neurodegenerative Disease Research Program Act. 8
- Section 2. Definitions. 9
- The following words and phrases when used in this act shall 10
- have the meanings given to them in this section unless the 11
- context clearly indicates otherwise: 12
- "Biorepository." An entity that receives, stores, processes 13
- or disseminates biospecimens, the derivatives of biospecimens or 14
- relevant data regarding biospecimens. 15



- "Department." The Department of Health of the Commonwealth.
- 2 "Eligible applicant." An institution engaged in
- 3 neurodegenerative disease research.
- 4 "Fund." The Neurodegenerative Disease Research Program Fund
- 5 established under section 5(a).
- 6 "Institution." Any of the following located in this
- 7 Commonwealth:
- 8 (1) An academic clinical research entity that conducts
- 9 neurodegenerative disease research.
- 10 (2) An institution of higher education that conducts
- 11 neurodegenerative disease research.
- 12 "Neurodegenerative disease." Conditions characterized by the
- 13 progressive loss of nerve cells in the brain or spinal cord,
- 14 leading to functional decline and often resulting in
- 15 debilitating conditions such as dementia or movement disorders,
- 16 including, but not limited to, amyotrophic lateral sclerosis,
- 17 Alzheimer's disease, Huntington's disease or Parkinson's
- 18 disease.
- "Neurodegenerative disease research." Health research on
- 20 neurodegenerative diseases. The term includes:
- 21 (1) Biomedical research.
- 22 (2) Clinical research.
- 23 (3) Health services research.
- 24 (4) Research regarding the establishment of a Statewide
- 25 biorepository.
- 26 (5) Research regarding a Statewide tissue bank.
- 27 "Program." The Neurodegenerative Disease Research Program
- 28 established under section 3(a).
- 29 "Tissue bank." An entity that is licensed, accredited or
- 30 regulated under Federal or State law to engage in the recovery,

- 1 screening, testing, processing, storage or distribution of
- 2 tissue.
- 3 Section 3. Neurodegenerative Disease Research Program.
- 4 (a) Establishment. -- The Neurodegenerative Disease Research
- 5 Program is established within the department.
- 6 (b) Purpose. -- The program shall provide grants to eligible
- 7 applicants to fund neurodegenerative disease research projects
- 8 on neurodegenerative disease and related infrastructure.
- 9 (c) Administration. -- The department shall implement and
- 10 administer the program in accordance with this act.
- 11 (d) Application form. --
- 12 (1) The department shall develop an application form
- which must be completed and approved before an eligible
- 14 applicant can receive a grant under the program.
- 15 (2) The application form under this subsection must
- 16 include:
- (i) Eligibility criteria to receive a grant under
- 18 the program.
- 19 (ii) Deadlines for submittal of a completed
- 20 application form.
- 21 (iii) Information to be submitted with a completed
- 22 application, including:
- 23 (A) Contact information.
- (B) Proof of eligibility for a grant under the
- 25 program.
- 26 (C) The purpose and amount of the requested
- 27 grant under the program.
- 28 (iv) Certification that the proposed research has
- 29 undergone appropriate Institutional Review Board review
- 30 and peer review as necessary.

- 1 (3) The department shall post the application form under
- 2 this subsection on its publicly accessible Internet website.
- 3 (e) Determination. -- The department shall develop a process
- 4 for:
- 5 (1) The submittal and review of a completed application
- form for grants under the program, including a timeline for
- 7 making a determination on the application and notice of the
- 8 award of grants under the program.
- 9 (2) The disbursement of grants under the program to
- 10 eligible applicants, including any limit on the amount of a
- 11 grant disbursed to an eligible applicant.
- 12 (3) The general administration of the program, including
- the maintenance of records regarding the program.
- 14 (f) Reports. -- Within 90 days after the grant period ends,
- 15 each recipient shall submit a report to the department which
- 16 shall include:
- 17 (1) The progress made in achieving expected research
- 18 goals and objectives.
- 19 (2) Any major discoveries, new drugs and new approaches
- for prevention, diagnosis and treatment which are
- 21 attributable to the completed research project.
- 22 (3) Any other information deemed necessary by the
- 23 department.
- 24 Section 4. Funding formula.
- 25 (a) Eligibility. -- If an institution has received funding for
- 26 neurodegenerative disease research from the National Institutes
- 27 of Health during any of the four preceding Federal fiscal years
- 28 in which money for that research was disbursed, the institution
- 29 shall be eligible to receive a grant under the program.
- 30 (b) Fund distribution. -- Money to be distributed to each

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- 1 eligible applicant shall be calculated by dividing the total
- 2 number of eligible applicants by the total amount appropriated
- 3 in a fiscal year.
- 4 Section 5. Neurodegenerative Disease Research Program Fund.
- 5 (a) Establishment. -- The Neurodegenerative Disease Research
- 6 Program Fund is established in the State Treasury to carry out
- 7 the purposes of the program.
- 8 (b) Operation. -- All money deposited into the fund and
- 9 interest and other earnings on the money in the fund are
- 10 appropriated to the department on a continuing basis to award
- 11 grants under the program.
- 12 (c) Fund sources. -- The department may solicit and accept
- 13 funding for the program, including money appropriated by the
- 14 General Assembly, Federal money, grants, donations, gifts and
- 15 other payments from any source, which shall be deposited into
- 16 the fund.
- 17 Section 6. Accountability.
- An eligible institution that receives a grant under the
- 19 program shall be subject to a performance review by the
- 20 department upon completion of a neurodegenerative disease
- 21 research project or more often as deemed necessary by the
- 22 department. The performance review shall be based on an
- 23 evaluation process by the department.
- 24 Section 7. Reports.
- 25 (a) Annual reports required. -- No later than September 1,
- 26 2025, and each September 1 thereafter, the department shall
- 27 issue an annual report detailing the operation of the program
- 28 and fund during the preceding year.
- 29 (b) Contents. -- Each annual report under this section must
- 30 include the following:

- 1 (1) The number of eligible applicants that sought a 2 grant under the program.
- 3 (2) The amount of the grant that each eligible applicant received under the program.
- 5 (3) The number of applicants that were denied, in whole 6 or in part, a grant under the program, including the reasons 7 for the full or partial denial.
- 8 (4) The money remaining in the fund.
- 9 (5) Any other information deemed necessary by the department.
- 11 (c) Transmittal.--Each annual report under this section 12 shall be transmitted to the following:
- 13 (1) The Governor.
- 14 (2) The President pro tempore of the Senate.
- 15 (3) The Speaker of the House of Representatives.
- 16 (4) The Minority Leader of the Senate.
- 17 (5) The Minority Leader of the House of Representatives.
- 18 (6) The chairperson and minority chairperson of the
- 19 Appropriations Committee of the Senate.
- 20 (7) The chairperson and minority chairperson of the
- 21 Appropriations Committee of the House of Representatives.
- 22 (d) Posting. -- The department shall post each annual report
- 23 under this section on the publicly accessible Internet website
- 24 of the department.
- 25 Section 8. Rules and regulations.
- The department shall adopt or promulgate rules or regulations
- 27 necessary to implement and administer this act.
- 28 Section 9. Effective date.
- 29 This act shall take effect immediately.

#### LEGISLATIVE REFERENCE BUREAU

AMENDMENTS TO HOUSE BILL NO. 704

Sponsor: Rep. Rossi - Dist. #59

Printer's No. 1437

#90

- 1 Amend Bill, page 2, lines 6 through 11, by striking out all
- 2 of said lines and inserting
- 3 "Institution." An academic clinical medical center located
- 4 in this Commonwealth that conducts neurodegenerative disease
- 5 research.
- 6 Amend Bill, page 3, line 29, by inserting after "review"
- 7 , Institutional Animal Care and Use Committee review
- 8 Amend Bill, page 4, line 27, by inserting after "Health"
- 9 or the Patient-Centered Outcomes Research Institute
- Amend Bill, page 5, by inserting between lines 3 and 4
- 11 (c) Funding limitations. -- Indirect costs shall be capped at
- 12 10% of grant funds.
- Amend Bill, page 5, lines 25 and 26, by striking out
- 14 "September 1, 2025," and inserting
- 15 December 31 of the year after the effective date of this
- 16 section
- Amend Bill, page 5, line 26, by striking out "September 1"
- 18 and inserting
- 19 December 31
- 20 Amend Bill, page 6, by inserting between lines 21 and 22
- 21 (8) The chairperson and minority chairperson of the
- 22 Health and Human Services Committee of the Senate.
- 23 (9) The chairperson and minority chairperson of the
- 24 Health Committee of the House of Representatives.

## HOUSE OF REPRESENTATIVES DEMOCRATIC COMMITTEE BILL ANALYSIS

Bill No:

HR0229 PN1617

Prepared By:

Patrick O'Rourke

(717) 787-4296,6711

Committee:

Health

**Executive Director:** 

Erika Fricke

Sponsor: Date:

5/13/2025

Hanbidge, Liz

## A. Brief Concept

Recognizes September 19, 2025, as "Aortic Disease Awareness Day."

#### **B. Committee Votes**

N/A.

## C. Analysis of the Bill

Aortic diseases and conditions include aortic stenosis, traumatic aortic ruptures, congenital and hereditary aortic defects such as Marfan syndrome and abdominal aortic aneurysms.

- More than 25,000 Americans die each year from aortic stenosis, the most common form
  of aortic disease, which occurs when a damaged valve either blocks or reduces the blood
  being pumped from the heart, causing heart and circulatory problems.
- A traumatic aortic rupture is the near-complete tear through all the layers of the aorta due to trauma.
- Aortic ruptures are the second-most common cause of death associated with motor vehicle accidents.
- Marfan syndrome is a genetic disorder that damages connective tissues and can cause heart problems.

Smoking is a major risk factor for developing aortic disease. Other risk factors include being over 50 years, a family history, and being male. Medicare Part A will cover surgeries and hospital stays, while Part B will cover prevention screenings, cardiac rehabilitation, counseling and exercise programs. Mitigating factors include refraining from tobacco products, a healthy diet, keeping blood pressure and cholesterol levels down and regular physical exercise.

## **Effective Date:**

N/A.

## D. Third Party Feedback

N/A.

## E. Prior Session (Previous Bill Numbers & House/Senate Votes)

N/A.

#### F. Key Points

Per the Mayo Clinic:

 Aortic valve disease is a type of heart valve disease. In this condition, the valve between the lower left heart chamber and the body's main artery doesn't work properly.

- The aortic valve helps keep blood flowing in the correct direction through the heart. A
  damaged or diseased aortic valve can affect blood flow to the rest of the heart and body.
  Aortic valve disease includes:
  - Aortic valve stenosis. Each heart valve has flaps of tissue that open and close once
    per heartbeat. The flaps also are called cusps. Sometimes the aortic valve flaps
    become thick and stiff, or they connect together. These problems cause the valve
    opening to become narrow. The narrowed valve reduces or blocks blood flow from
    the heart to the rest of the body.
  - Aortic valve regurgitation. The aortic valve doesn't close properly, causing blood to flow backward into the left lower heart chamber.

## G. Relevant Existing Laws

N/A.

## H. Messaging

N/A.

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## THE GENERAL ASSEMBLY OF PENNSYLVANIA

# HOUSE RESOLUTION

<sub>No.</sub> 229

Session of 2025

INTRODUCED BY HANBIDGE, VENKAT, HILL-EVANS, SANCHEZ, FREEMAN, KHAN, HOHENSTEIN, D. WILLIAMS AND NEILSON, MAY 5, 2025

REFERRED TO COMMITTEE ON HEALTH, MAY 6, 2025

#### A RESOLUTION

- Recognizing September 19, 2025, as "Aortic Disease Awareness Day" in Pennsylvania.
- 3 WHEREAS, The aorta is the largest artery in the body,
- 4 originating just after the aortic valve, and it is connected to
- 5 the heart, extends through the entire chest and abdomen and
- 6 carries oxygenated blood away from the heart to supply the body;
- 7 and
- 8 WHEREAS, There are multiple aortic diseases and conditions,
- 9 including aortic stenosis, traumatic aortic ruptures, congenital
- 10 and hereditary aortic defects such as Marfan syndrome and
- 11 abdominal aortic aneurysms; and
- WHEREAS, More than 25,000 Americans die each year from aortic
- 13 stenosis, the most common form of aortic disease, which occurs
- when a damaged valve either blocks or reduces the blood being
- 15 pumped from the heart, causing heart and circulatory problems;
- 16 and
- WHEREAS, A traumatic aortic rupture is the near-complete tear
- 18 through all the layers of the aorta due to trauma such as that

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- 1 sustained in a motor vehicle collision or a fall; and
- 2 WHEREAS, Aortic ruptures are the second-most common cause of
- 3 death associated with motor vehicle accidents; and
- WHEREAS, Marfan syndrome is a genetic disorder that damages
- 5 connective tissues and can cause heart problems; and
- 6 WHEREAS, One in 5,000 people have this condition with a 50%
- 7 chance they will pass it on to the next generation; and
- 8 WHEREAS, More than 13,000 Americans die each year as a result
- 9 of abdominal aortic aneurysms, a condition in which there is
- 10 plaque buildup in the walls of the abdominal aorta, causing it
- 11 to become weak and build up like a balloon; and
- 12 WHEREAS, A major risk factor for the development of aortic
- 13 diseases is smoking, and more than 90% of patients with such
- 14 aneurysms have been smokers; and
- WHEREAS, Other risk factors include being older than 50 years
- 16 of age, being male as occurrence in males is 4 to 5 times
- 17 greater than that of females, a family history with abdominal
- 18 aortic aneurysm, genetic factors, high cholesterol, high blood
- 19 pressure, diabetes and obesity; and
- 20 WHEREAS, Medicare Part A will cover surgeries and hospital
- 21 stays, while Part B will cover prevention screenings, cardiac
- 22 rehabilitation, counseling and exercise programs; and
- 23 WHEREAS, Treatment for aortic conditions includes monitoring
- 24 with MRI or CT scans, controlling high blood pressure and
- 25 lowering cholesterol, abdominal aortic aneurysm open repair or
- 26 endovascular aneurysm repair; and
- 27 WHEREAS, Prevention of aortic conditions from occurring or
- 28 worsening entails refraining from using tobacco products,
- 29 maintaining a healthy diet, keeping blood pressure and
- 30 cholesterol under control and regular physical exercise; and

- 1 WHEREAS, "Aortic Disease Awareness Day" seeks to educate
- 2 Pennsylvanians about the health risks associated with the
- 3 asymptomatic and lethal condition; and
- WHEREAS, As a Commonwealth, we can take the appropriate steps
- 5 to identify and prevent serious complications due to aortic
- 6 conditions in this Commonwealth; and
- 7 WHEREAS, "Aortic Disease Awareness Day" provides the
- 8 opportunity for residents of this Commonwealth to show support
- 9 for aging adults living with abdominal aortic aneurysms by
- 10 educating people on the condition, promoting health screenings,
- 11 encouraging a healthy lifestyle and commemorating the loved ones
- 12 lost to aortic diseases; therefore be it
- 13 RESOLVED, That the House of Representatives recognize
- 14 September 19, 2025, as "Aortic Disease Awareness Day" in
- 15 Pennsylvania.

# HOUSE OF REPRESENTATIVES DEMOCRATIC COMMITTEE BILL ANALYSIS

Bill No:

HR0232 PN1672

McAndrew, Joe

Prepared By:

Patrick O'Rourke

(717) 787-4296,6711

Committee:
Sponsor:

Health

Executive Director:

Erika Fricke

Date:

5/13/2025

## A. Brief Concept

Recognizes May 15, 2025, through June 15, 2025, as "Tourette Syndrome Awareness Month."

#### **B.** Committee Votes

N/A.

## C. Analysis of the Bill

Tourette syndrome (TS) is a neurodevelopmental disorder characterized by sudden, involuntary movements or vocalizations known as tics, which typically emerge between 5 and 10 years of age. One out of 50 children between 5 and 17 in the U.S. has TS or related disorder, however, many cases go undiagnosed. Co-occurring conditions such as attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, anxiety disorders and learning disabilities often further complicate diagnosis. There is no known cure for TS however medications, behavioral treatments and psychotherapy can help individuals control tics, manage symptoms and cope with the syndrome. Additionally, increased awareness can improve early diagnosis, promote access to necessary treatments and foster a more inclusive and supportive environment for individuals with TS.

## **Effective Date:**

N/A.

## D. Third Party Feedback

N/A.

#### E. Prior Session (Previous Bill Numbers & House/Senate Votes)

N/A.

#### F. Key Points

Per the Mayo Clinic:

- Tourette (too-RET) syndrome is a disorder that involves repetitive movements or unwanted sounds (tics) that can't be easily controlled. For instance, you might repeatedly blink your eyes, shrug your shoulders or blurt out unusual sounds or offensive words.
- Tics typically show up between ages 2 and 15, with the average being around 6 years of age. Males are about three to four times more likely than females to develop Tourette syndrome.
- Although there's no cure for Tourette syndrome, treatments are available. Many people with Tourette syndrome don't need treatment when symptoms aren't troublesome. Tics often lessen or become controlled after the teen years.

#### G. Relevant Existing Laws

N/A.

## H. Messaging

N/A.

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## THE GENERAL ASSEMBLY OF PENNSYLVANIA

## HOUSE RESOLUTION

No. 232 Session of

INTRODUCED BY McANDREW, GIRAL, PROBST, BURGOS, HILL-EVANS, VENKAT, BRENNAN, MCNEILL, STAATS, SANCHEZ, COOPER, NEILSON, O'MARA, DELLOSO AND FLEMING, MAY 8, 2025

REFERRED TO COMMITTEE ON HEALTH, MAY 8, 2025

#### A RESOLUTION

- Recognizing May 15, 2025, through June 15, 2025, as "Tourette 1 Syndrome Awareness Month" in Pennsylvania to raise public 2 awareness, promote acceptance and support individuals living 3 with Tourette syndrome and related disorders. 4 WHEREAS, Tourette syndrome (TS) is a neurodevelopmental 5 disorder characterized by sudden, involuntary movements or vocalizations known as tics, which typically emerge between 5 and 10 years of age; and WHEREAS, It is estimated that 1 out of every 50 children 9 between 5 and 17 years of age in the United States has TS or a 10 related tic disorder, yet many cases go undiagnosed or 11 misdiagnosed due to a lack of public and medical awareness; and 12 WHEREAS, TS often coexists with other conditions such as 13 attention-deficit/hyperactivity disorder, obsessive-compulsive 14
- disorder, anxiety disorders and learning disabilities, creating 15
- unique challenges in education, employment and social 16
- interactions; and 17
- WHEREAS, Individuals with TS frequently experience stigma, 18



- 1 discrimination and misunderstanding, which can lead to social
- 2 isolation and difficulty accessing appropriate medical and
- 3 educational support; and
- WHEREAS, Although there is no cure for TS, medications,
- 5 behavioral treatments and psychotherapy can help individuals
- 6 control tics, manage symptoms and cope with the syndrome; and
- 7 WHEREAS, Increased awareness and understanding of TS can
- 8 improve early diagnosis, promote access to necessary treatments
- 9 and foster a more inclusive and supportive environment for
- 10 individuals with TS; and
- 11 WHEREAS, "Tourette Syndrome Awareness Month," observed
- 12 annually from May 15 to June 15, seeks to educate the public,
- 13 reduce stigma and support research efforts aimed at improving
- 14 the lives of those affected by TS; therefore be it
- RESOLVED, That the House of Representatives recognize May 15,
- 16 2025, through June 15, 2025, as "Tourette Syndrome Awareness
- 17 Month" in Pennsylvania to raise public awareness, promote
- 18 acceptance and support individuals living with Tourette syndrome
- 19 and related disorders.