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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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HOUSE RESOLUTION

No. 433 Session of  
2024

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INTRODUCED BY MALAGARI, CONKLIN, SANCHEZ, HILL-EVANS, ROZZI,  
NEILSON AND KINSEY, MAY 14, 2024

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REFERRED TO COMMITTEE ON HEALTH, MAY 14, 2024

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A RESOLUTION

1 Recognizing May 17, 2024, as "World Neurofibromatosis Awareness  
2 Day" in Pennsylvania.

3 WHEREAS, The Children's Tumor Foundation is observing May 17,  
4 2024, as "World Neurofibromatosis Awareness Day" to educate the  
5 public about this rare genetic condition; and

6 WHEREAS, The global community recognizes the importance of  
7 raising awareness about neurofibromatosis, its impact on  
8 individuals and families and the need for continued research and  
9 support; and

10 WHEREAS, Although more than 4 million people around the world  
11 are living with neurofibromatosis and 1 in every 2,000 births is  
12 diagnosed with neurofibromatosis, it is still relatively unknown  
13 to the public; and

14 WHEREAS, Neurofibromatosis affects all populations equally,  
15 regardless of race, ethnicity or gender; and

16 WHEREAS, Neurofibromatosis causes tumors to grow on nerves  
17 throughout the body and also can affect development of the  
18 brain, cardiovascular system, bones and skin; and

1       WHEREAS, The disorder can lead to blindness, deafness, bone  
2       abnormalities, disfigurement, learning disabilities, disabling  
3       pain and cancer; and

4       WHEREAS, There are three different types of  
5       neurofibromatosis: neurofibromatosis type 1, neurofibromatosis  
6       type 2 and schwannomatosis; and

7       WHEREAS, Signs of neurofibromatosis type 1 include light  
8       brown spots on the skin, known as café au lait spots, bumps  
9       known as Lisch nodules on the iris of the eye and freckles on  
10      the groin or armpits; and

11      WHEREAS, Neurofibromatosis type 1 is one of the country's  
12      most common genetic disorders occurring in approximately 1 in  
13      2,500 births; and

14      WHEREAS, Neurofibromatosis type 2 is far less common,  
15      occurring in 1 in 60,000 people, and is typically characterized  
16      by tumors that grow on the nerves of the inner ear; and

17      WHEREAS, Schwannomatosis is a rarer form of neurofibromatosis  
18      for which symptoms typically appear between ages 25 and 30; and

19      WHEREAS, Schwannomatosis often forms on the spinal or cranial  
20      nerves and leads to symptoms like chronic pain or loss of  
21      muscle; and

22      WHEREAS, Instances of neurofibromatosis occur due to  
23      mutations that either occur during conception or are passed down  
24      genetically through the parents; and

25      WHEREAS, Family history, physical exams and genetic tests are  
26      currently used to diagnose neurofibromatosis in patients; and

27      WHEREAS, While there is currently no cure available, there  
28      are multiple forms of treatment for patients dealing with  
29      neurofibromatosis; and

30      WHEREAS, Mild instances of neurofibromatosis often do not

1 require significant treatment outside of regular doctor visits  
2 and observation; and

3 WHEREAS, More severe cases may require removal through  
4 radiation or surgery done by a nerve tumor specialist or a team  
5 of various surgeons; and

6 WHEREAS, There are currently no medications that have been  
7 approved to treat neurofibromatosis, though researchers are  
8 investigating various methods and therapies; and

9 WHEREAS, The Children's Tumor Foundation leads efforts to  
10 promote and financially sponsor world-class medical research  
11 aimed at finding effective treatments and, ultimately, a cure  
12 for neurofibromatosis; and

13 WHEREAS, The Children's Tumor Foundation is connecting the  
14 unconnected, leading the way through innovative and inventive  
15 approaches to scientific advancement and improved patient care,  
16 revamping systems to accelerate the path from discovery to  
17 treatment; and

18 WHEREAS, The Children's Tumor Foundation provides patient and  
19 family support through its information resources, youth programs  
20 and community activities; and

21 WHEREAS, Much remains to be done in raising public awareness  
22 of neurofibromatosis to help promote early diagnosis, proper  
23 management and treatment, prevention of complications and  
24 support for research; therefore be it

25 RESOLVED, That the House of Representatives recognize May 17,  
26 2024, as "World Neurofibromatosis Awareness Day" in  
27 Pennsylvania.