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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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# SENATE RESOLUTION

No. 365 Session of  
2018

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INTRODUCED BY LANGERHOLC, SABATINA, GREENLEAF, MARTIN,  
BARTOLOTTA, RESCHENTHALER, DINNIMAN, BREWSTER, BROWNE,  
FOLMER, FARNESE, AUMENT, HUTCHINSON, HUGHES, SCHWANK,  
KILLION, RAFFERTY, VULAKOVICH, MENSCH, BLAKE AND COSTA,  
MAY 22, 2018

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INTRODUCED AND ADOPTED, MAY 22, 2018

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## A RESOLUTION

1 Designating the month of May 2018 as "Neurofibromatosis  
2 Awareness Month" in Pennsylvania.

3 WHEREAS, Neurofibromatosis (NF) is a genetically determined  
4 neurological disorder having familial or sporadic origin; and

5 WHEREAS, NF carries a risk of highly variable physical,  
6 mental and quality-of-life complications; and

7 WHEREAS, Specific complications may have a minimal, disabling  
8 or fatal effect; and

9 WHEREAS, NF affects an estimated 100,000 people nationwide;  
10 and

11 WHEREAS, Abnormalities of the brain, spinal cord, nerves and  
12 skin increase the incidence of benign or malignant tumor growth;  
13 and

14 WHEREAS, Orthopedic manifestations affect postural control,  
15 bone formation and bone density; and

16 WHEREAS, Children with NF have higher rates of intellectual

1 and learning disabilities than other children; and

2 WHEREAS, NF represents three genetically distinct disorders;  
3 and

4 WHEREAS, Type 1 (NF1), classified as a tumor predisposition  
5 syndrome, is a progressive disorder usually diagnosed in  
6 childhood; and

7 WHEREAS, Diagnosis is based on physical findings relating to  
8 a child's skin, eyes, bones and brain; and

9 WHEREAS, The presence of internal and external tumors and  
10 areas of abnormal skin color characterize NF1; and

11 WHEREAS, Combination drugs may moderate NF1-linked drug  
12 resistance mechanisms; and

13 WHEREAS, Type 2 (NF2) causes peripheral neuropathy and  
14 deteriorating balance and hearing; and

15 WHEREAS, Slow-growing tumors on cranial nerves distinguish  
16 NF2; and

17 WHEREAS, Early onset of NF2 symptoms has an adverse effect on  
18 long-term survival; and

19 WHEREAS, Schwannomatosis (SWN), the third type, has two known  
20 causative genes which give rise to benign tumors; and

21 WHEREAS, SWN induces intense neuropathic pain, numbness and  
22 weakness; and

23 WHEREAS, No targeted therapies reverse NF expression; and

24 WHEREAS, Primary care providers, genetic counselors, physical  
25 therapists, radiation therapists and behavioral therapists  
26 contribute to patient-centered care teams; and

27 WHEREAS, NF treatment plans may include pain control,  
28 chemotherapy and surgical resection of tumors; and

29 WHEREAS, Education and counseling along with monitoring of  
30 local, systemic and chronic symptoms and neurocognitive

1 impairments are other elements of NF care; and

2 WHEREAS, Survival rates are improving with earlier diagnosis,  
3 advances in molecular biology and neuroimaging, specialized  
4 treatment centers and NF-specific research teams; and

5 WHEREAS, These teams investigate gene regulation, immune  
6 markers, nutrient intake, tumor suppressor proteins, pain  
7 intensity and drug safety; and

8 WHEREAS, Each NF syndrome is an orphan disease, and each NF  
9 patient is unique, making precision medicine and identification  
10 of genetic, epigenetic and environmental risk factors priorities  
11 for continued research; therefore be it

12 RESOLVED, That the Senate designate the month of May 2018 as  
13 "Neurofibromatosis Awareness Month" in Pennsylvania.