

---

THE GENERAL ASSEMBLY OF PENNSYLVANIA

---

SENATE RESOLUTION

No. 123 Session of  
2019

---

INTRODUCED BY LANGERHOLC, BARTOLOTTA, STEFANO, BROWNE, VOGEL,  
PHILLIPS-HILL, MARTIN, J. WARD, KILLION, SCAVELLO, FOLMER,  
DINNIMAN, TARTAGLIONE, FONTANA, BREWSTER, KEARNEY, SCHWANK,  
HUGHES AND COSTA, MAY 8, 2019

---

INTRODUCED AND ADOPTED, MAY 8, 2019

---

A RESOLUTION

1 Designating the month of May 2019 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  
17 and learning disabilities than other children; and

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

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

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

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

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

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

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

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

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

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

22       WHEREAS, No targeted therapies reverse NF expression; and

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

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

28       WHEREAS, Education and counseling along with monitoring of  
29 local, systemic and chronic symptoms and neurocognitive  
30 impairments are other elements of NF care; and

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

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

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

11       RESOLVED, That the Senate designate the month of May 2019 as  
12 "Neurofibromatosis Awareness Month" in Pennsylvania.