
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 365 Session of
2018

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

INTRODUCED AND ADOPTED, MAY 22, 2018

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.