

BY: M. of A. McDonald

MEMORIALIZING Governor Kathy Hochul to proclaim May 2025, as Neurofibromatosis Month in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official months that are set aside to increase awareness of serious illnesses that affect the lives of citizens of New York State; and

WHEREAS, This Legislative Body is justly proud to memorialize Governor Kathy Hochul to proclaim May 2025, as Neurofibromatosis Month in the State of New York, in conjunction with the observance of National Neurofibromatosis Month; and

WHEREAS, Neurofibromatosis (NF), a debilitating tumor disorder, affects more than 130,000 Americans; and

WHEREAS, Neurofibromatosis Northeast has worked for over 30 years on its mission to find a cure for NF; and

WHEREAS, With a mission to finding a treatment and cure for NF, Neurofibromatosis Northeast promotes research, creates awareness and supports those who are affected by NF; and

WHEREAS, Growing awareness of NF has resulted in increased investment in research through private charities such as NF Northeast and the NF Research Program in the Department of Defense which has resulted in new clinical trials involving application of drugs which have been shown to reduce malignant tumors in cancer; and

WHEREAS, In 2019, the FDA approved the use of Koselugo (selumetinib) for treatment of NF1, and promising science using combination therapy, gene therapy and bacterial therapy has led to new clinical trials offering hope for families dealing with the uncertainties of NF; and

WHEREAS, Increased knowledge of NF will help initiate critical research; NF patients and their families are determined to make Neurofibromatosis a household word; and

WHEREAS, Proliferation of awareness about NF has helped educate clinicians regarding the disease and treatment, and has enhanced opportunities for patients to receive treatment from knowledgeable local clinicians such as Drs. Lauren Weintraub and Katharine Halligan of the Melodies Center at Albany Medical Center; and

WHEREAS, It is imperative that there be greater awareness of this serious health condition, and more must be done to increase activity at the local, State and National levels; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim May 2025, as

Neurofibromatosis Month in the State of New York; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Kathy Hochul, Governor of the State of New York.