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Neurofibromatosis Awareness Month, 1989

By the President of the United States of America

A Proclamation

Neurofibromatosis is a potentially debilitating genetic disorder that causes tumors to develop in nervous system tissues. It affects one in 3,700 Americans. There are two known types of neurofibromatosis. The great majority of patients have NF-1, characterized by six or more dark patches on the skin and by tumors on peripheral nerves. The tumors can be severely disfiguring and painful and can also result in bone deformations and visual impairment. In the less common NF-2, tumors occur within the central nervous system, usually damaging nerves crucial to hearing and balance.

Individuals with neurofibromatosis, their families, and the health professionals who help them can all benefit from new guidelines for the diagnosis and management of this condition developed last year in a consensus conference at the National Institutes of Health. At the conference, scientists studying the genetics of neurofibromatosis presented particularly encouraging findings: They have determined that the gene defect that causes NF-1 lies on chromosome 17, and the defect for NF-2 on chromosome 22. These discoveries, medical experts agree, should soon lead to the development of diagnostic tests capable of definitively detecting neurofibromatosis gene carriers. As more is learned about the genetic defects in neurofibromatosis, scientists will be better able to design treatment strategies to assist those afflicted.

Private voluntary health agencies, chiefly the National Neurofibromatosis Foundation, are partners with the National Institute of Neurological and Communicative Disorders and Stroke in the fight against this tragic disorder. Countless families have been sustained and encouraged by support groups established by these agencies in most large American cities. These agencies also play an essential role in informing the health care professions and the general public about neurofibromatosis, about the needs of patients and families, and about the positive actions we can all undertake to ease their burdens.

To enhance public awareness of neurofibromatosis, the Congress, by House Joint Resolution 417, has designated May 1989 as "Neurofibromatosis Awareness Month" and authorized and requested the President to issue a proclamation in observance of that occasion.

NOW, THEREFORE, I, RONALD REAGAN, President of the United States of America, do hereby proclaim May 1989 as Neurofibromatosis Awareness Month. I call upon the people of the United States to observe this month with appropriate ceremonies and activities.

IN WITNESS WHEREOF, I have hereunto set my hand this twenty-second day of August, in the year of our Lord nineteen hundred and eighty-eight, and of the Independence of the United States of America the two hundred and thirteenth.

Ronald Reagan