

STATE OF MAINE

IN THE YEAR OF OUR LORD

TWO THOUSAND TWENTY-THREE

**JOINT RESOLUTION RECOGNIZING MAY 17, 2023 AS WORLD
NEUROFIBROMATOSIS AWARENESS DAY**

WHEREAS, the Children's Tumor Foundation is observing May 17, 2023 as World Neurofibromatosis Awareness Day to educate the public about this rare genetic disorder; and

WHEREAS, although over 2 million people around the world are living with neurofibromatosis and one in every 3,000 newborns is diagnosed with neurofibromatosis, it is still is relatively unknown to the public; and

WHEREAS, neurofibromatosis affects all populations equally, regardless of race, ethnicity or gender; and

WHEREAS, neurofibromatosis causes tumors to grow on nerves throughout the body and also can affect development of the brain, cardiovascular system, bones and skin; and

WHEREAS, the disorder can lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain and cancer; and

WHEREAS, the Children's Tumor Foundation leads efforts to promote and financially sponsor world-class medical research aimed at finding effective treatments and, ultimately, a cure for neurofibromatosis; and

WHEREAS, the Children's Tumor Foundation is leading the way through innovative and inventive approaches to scientific advancement and improved patient care, revamping systems to accelerate the path from discovery to treatment; and

WHEREAS, the Children's Tumor Foundation works to improve access to quality patient care through its national neurofibromatosis clinic network; and

WHEREAS, the Children's Tumor Foundation provides patient and family support through its information resources, youth programs and community activities; and

WHEREAS, much remains to be done in raising public awareness of neurofibromatosis to help promote early diagnosis, proper management and treatment, prevention of complications and support for research; now, therefore, be it

RESOLVED: That We, the Members of the One Hundred and Thirty-first Legislature now assembled in the First Special Session, on behalf of the people we represent, take this opportunity to recognize May 17, 2023 as World Neurofibromatosis Awareness Day.