

**Proclamation** In Recognition of

## World Neurofibromatosis Awareness Day

WHEREAS, neurofibromatosis (NF) refers to three genetic disorders – NF1, NF2, and schwannomatosis – that affect over 125,000 people in the United States and over 2.5 million worldwide; and

WHEREAS, NF causes tumors to grow on nerves throughout the body which causes health problems by pressing on nearby body tissues, and can lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, and disabling pain; and

WHEREAS, NF1 is characterized by multiple café-au-lait (light brown) spots on the skin, neurofibromas (small benign growths) on or under the skin, freckling in the armpits or groin, softening and curving of bones and curvature of spine, tumors on cranial nerves or spinal cord, and/or learning challenges; and

WHEREAS, NF2 is characterized by benign tumors on the nerve that carries sound from the inner ear to the brain, often leading to hearing loss, tinnitus (ringing in the ears), and/or development of cataracts or eye abnormalities; and

**WHEREAS**, schwannomatosis is rare, characterized by benign tumors on spinal and peripheral nerves, causing pain that may be hard to manage; and

WHEREAS, the types and severity of NF symptoms vary from person to person; and

**WHEREAS**, the Children's Tumor Foundation, which provides patient and family support through its information resources, youth programs, and local chapter activities, is committed to finding effective treatments for people living with NF and works to improve access to quality patient healthcare through its national NF Clinic Network; and

WHEREAS, the Children's Tumor Foundation celebrates World NF Awareness Day to foster hope in the NF community, promote research funding, and raise awareness of this genetic disorder;

THEREFORE I, DAVID Y. IGE, Governor, and I, DOUGLAS S. CHIN, Lieutenant Governor of the State of Hawai'i, do hereby proclaim May 17, 2018 as

## **"NEUROFIBROMATOSIS AWARENESS DAY"**

in Hawai'i and ask the people of the Aloha State to join us in supporting the NF community in the fight against neurofibromatosis, recognize the challenges that NF patients face in their daily lives, and applaud their positive spirit, perseverance and strength.

**DONE** at the State Capitol, in Executive Chambers, Honolulu, State of Hawai'i, this sixteenth day of May 2018.

DAVID

Governor, State of Hawai'i

DOUGLA Lt. Governor, State of Hawai'i