Proclamation by Governor Jim Justice

Whereas, it takes an average of 3.6 years to get an accurate diagnosis of Frontotemporal Degeneration with average life expectancy 7-13 years after the start of symptoms; and

Whereas, Frontotemporal Degeneration imposes average annual costs associated with care and living with the disease that are approximately double those of Alzheimer's Disease; and

Whereas, Frontotemporal Degeneration is identified in The National Plan to Address Alzheimer's Disease as a related dementia and is included as a priority in the goals and strategies of The Plan to achieve the vision of a nation free of Alzheimer's Disease and Related Dementias; and

Whereas, Frontotemporal Degeneration represents an estimated 5-15% of all dementia cases and is the most common form for those diagnosed with dementia for people under 60 years of age; and

Whereas, approximately 40% of people with Frontotemporal Degeneration have a family history or a related condition such as ALS, about half of those found to have an inherited form accounted for by mutations in the Progranulin, C9orf72, Tau/MAPT or other rarer genes; and

Whereas, Frontotemporal Degeneration is often misdiagnosed as a psychiatric condition or other neurodegenerative disease due to the wide range of cognitive and behavioral symptoms along with often younger onset; and

Whereas, while there has never been a global epidemiology study of Frontotemporal Degeneration, it is estimated that more than 60,000 people are affected in the United States today; and

Whereas, the Association for Frontotemporal Degeneration (AFTD) reports that Frontotemporal Degeneration (FTD) is an incurable, terminal neurodegenerative disease affecting the frontal and temporal lobes of the brain, causing impairments to speech, behavior, judgment, personality and motor skills which constitutes a major public health concern; and

Whereas, the AFTD is the leading national organization solely focused on the spectrum of Frontotemporal Degeneration disorders with a mission to improve the quality of life of people affected by Frontotemporal Degeneration with support, education, raising awareness of and advocating for those affected by Frontotemporal Degeneration while driving research to a cure;

Whereas, it is imperative that there be greater awareness of this terminal disease, and more must be done to increase activity for such at the local, state, and national levels.

Now, Therefore, Be it Resolved that I, Jim Justice, Governor of the Great State of West Virginia, do hereby proclaim September 22-29, 2024 as:

Frontotemporal Degeneration Awareness Week

in the Mountain State and encourage all citizens to join me in observance.

In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of West Virginia to be affixed.

Done at the Capitol, City of Charleston, State of West Virginia, this the Twenty-Fifth day of June, in the year of our Lord, Two Thousand Twenty-Four, and in the One Hundred Sixty-Second year of the State.

Jim Justice Governor

By the Governor:

Mac Warner Secretary of State