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HOUSE JOINT RESOLUTION NO. 551

Offered January 27, 2025

*Commending the Edwards family.*_____
Patron—Ware

WHEREAS, the Edwards family of Midlothian has worked diligently to raise awareness of Frontotemporal Degeneration to honor the memory of Steve Edwards, a highly respected firefighter and beloved husband and father, who died from the disease in 2023; and

WHEREAS, Frontotemporal Degeneration represents as many as 15 percent of all cases of dementia and is the most common form of dementia affecting individuals younger than 60 years of age; and

WHEREAS, Frontotemporal Degeneration (FTD) is an incurable and terminal neurodegenerative disease that affects the frontal and temporal lobes, causing impairments to speech, personality, behavior, and motor skills; and

WHEREAS, though now better diagnosed than previously, those afflicted with FTD must wait well over three years from the onset of symptoms to receive a definitive diagnosis by specialized physicians; and

WHEREAS, Frontotemporal Degeneration has often previously been misdiagnosed as a psychiatric disorder or neurodegenerative disease, simply because of FTD's wide range of cognitive and behavioral symptoms manifesting themselves at a fairly young age; and

WHEREAS, more than 60,000 Americans are affected by FTD; though the disease may strike individuals between the ages of 21 and 80, the highest percentage of those afflicted are between the ages of 45 and 64; and

WHEREAS, FTD affects a person's ability to express emotion, show affection, speak, maintain muscle strength, and swallow and, in sum, has a devastating impact on the entire personality, rendering individuals in the prime of life unable to live a normal life or maintain a livelihood; and

WHEREAS, the cost of care for individuals with FTD is estimated at twice that required for individuals with better-known Alzheimer's Disease; and

WHEREAS, the Association for Frontotemporal Degeneration is the leading association advocating for increased awareness of the nature and effects of FTD; and

WHEREAS, Carrie Edwards of Midlothian is spearheading efforts within the Commonwealth to increase awareness of Frontotemporal Degeneration; and

WHEREAS, Carrie Edwards and her late husband, Steve, were sweethearts from their high school days together; they married in 1976, and a year later he enrolled in the 40th Recruit School of the Fairfax County Fire Department; and

WHEREAS, Steve Edwards, a career firefighter, was, in the eyes of comrades and family, a "9/11 hero" as he was called to serve as battalion chief on site at the Pentagon in response to the terrorist attacks of September 11, 2001; and

WHEREAS, at age 59, Steve Edwards was stricken with FTD, but the condition was not fully diagnosed for two full years, whereupon the Edwards family's journey with the effects of FTD began in earnest; and

WHEREAS, though the once vibrant firefighter, husband, father, and friend "melted away" over ensuing years, his "final act of courage," Carrie Edwards recounts, was to walk the couple's daughter down the aisle for her marriage in December 2023; and

WHEREAS, Steve Edwards passed away on December 31, 2023, and donated his brain to Mayo Clinic as a means of "helping others suffering from this devastating form of dementia"; and

WHEREAS, on September 21–28, 2025, the Edwards family and other individuals and families who have been affected by the disease will recognize Frontotemporal Degeneration Awareness Week; and

WHEREAS, Frontotemporal Degeneration Awareness Week provides an opportunity for all Virginians to learn more about this singular form of dementia, support research into treatments and a cure, and offer comfort to those who have been affected by the disease; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the General Assembly hereby commend the Edwards family for their outstanding achievements in raising awareness of Frontotemporal Degeneration and bringing hope and support to people living with the disease and their families; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates prepare a copy of this resolution for presentation to Carrie Edwards as an expression of the General Assembly's admiration for the Edwards family's kindness, compassion, and dedication to serving others.

INTRODUCED

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