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HOUSE RESOLUTION NO. 486

Offered January 17, 2025

Commending Ryan Alam and the Alam family.

Patron—Reaser

WHEREAS, Ryan Alam and the Alam family of Sterling have worked diligently to raise awareness of neurodegeneration with brain iron accumulation and led efforts to increase research into this extremely rare but debilitating disease; and

WHEREAS, after years of living with an unknown, painful, and progressive condition, Ryan Alam was diagnosed with a type of neurodegeneration with brain iron accumulation (NBIA) known as mitochondrial membrane protein-associated neurodegeneration (MPAN); and

WHEREAS, since 2001, there have been only approximately 500 cases of NBIA around the world, less than 100 of which are MPAN; the disease can lead to a loss of motor functions like walking, can cause problems with vision, and can lead to the development of dementia and Parkinson's disease; and

WHEREAS, after learning that there is no known cure for NBIA and very little active research, Ryan Alam and his family sought to bring attention to this rare condition and raise money to help find treatments and a cure; and

WHEREAS, Ryan Alam has inspired others through his courage, sense of adventure, and joy for life, and he is determined to help other individuals living with NBIA; the Alam family began working with a team of doctors and researchers at Children's National Hospital in Washington, D.C., to lay the groundwork for comprehensive study into the disease; and

WHEREAS, Ryan Alam's parents, Tuba and Faisal Alam have worked diligently to explain NBIA and MPAN to potential donors and built strong relationships that have helped their search for a cure grow into a movement with the potential to effect lasting change; and

WHEREAS, Ryan Alam's sister, Sonia, has also demonstrated a grace and resiliency beyond her years, both by supporting her brother and by providing a cheerful presence at events and fundraisers; and

WHEREAS, through their visionary leadership and exceptional accomplishments, Ryan Alam and the Alam family have raised more than \$385,000 for Children's National Hospital's Help Cure NBIA-MPAN fund; now, therefore, be it

RESOLVED by the House of Delegates, That Ryan Alam and the Alam family hereby be commended for their work to raise awareness of neurodegeneration with brain iron accumulation and provide hope and support to people living with this rare condition; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates prepare a copy of this resolution for presentation to Ryan Alam and the Alam family as an expression of the House of Delegates' admiration for their inspirational dedication to serving others.

INTRODUCED

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