

## 2019 SESSION

INTRODUCED

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### HOUSE RESOLUTION NO. 430

Offered February 21, 2019

*Commending Jana Monaco.*

Patron—Murphy

WHEREAS, Jana Monaco has served as the Rare Action Network State Ambassador for Virginia with the National Organization of Rare Disorders since 2016; and

WHEREAS, in 2000, Jana Monaco suffered an unimaginable tragedy when her three-year-old son, Stephen, went into a critical state overnight and slipped into a coma while hospitalized; the cause was determined to be isovaleric acidemia, a rare genetic condition that prohibits the body from breaking down the amino acid leucine, a byproduct of protein; and

WHEREAS, Stephen emerged from the coma, but his life would never be the same; at the hospital, Jana Monaco vowed that her son's plight would not be in vain; and

WHEREAS, Jana Monaco became an advocate for newborn screenings that would detect rare disorders and prevent conditions like Stephen's; she spoke before numerous organizations including the Virginia Genetics Advisory Committee, the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children, and the Northern Virginia Pediatric Society; and

WHEREAS, for over 14 years, Jana Monaco has served as co-chair of the Children's National Hospital Center's Patient and Family Advisory Council; she has also been a panel member for the National Genetic Policy Summit and served on the Health Resources and Services Administration Advisory Committee for Heritable Disorders and Genetic Diseases; and

WHEREAS, these efforts helped the passage of the Newborn Screening Saves Lives Act in 2008 and a reauthorization bill in 2015; in 1997, Virginia newborns were only screened for nine genetic disorders; by 2016, every state in the country screened newborns for at least 29 genetic disorders; and

WHEREAS, as the Rare Action Network State Ambassador for Virginia with the National Organization of Rare Disorders, Jana Monaco is responsible for establishing a strong grassroots network of rare disease advocates within the state to increase awareness of rare diseases and the challenges parents and their families face; and

WHEREAS, Jana Monaco's efforts have saved thousands of lives and prevented untold, needless suffering; now, therefore, be it

RESOLVED by the House of Delegates, That Jana Monaco hereby be commended for her service as the Rare Action Network State Ambassador for Virginia with the National Organization of Rare Disorders; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates prepare a copy of this resolution for presentation to Jana Monaco as an expression of the House of Delegates' admiration for her contributions to the Commonwealth.

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