

2021 SESSION

INTRODUCED

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HOUSE JOINT RESOLUTION NO. 607

Offered January 21, 2021

Designating May, in 2021 and in each succeeding year, as Cystic Fibrosis Awareness Month in Virginia.

Patrons—Subramanyam, Murphy, Adams, D.M., Avoli, Ayala, Carter, Cole, J.G., Cole, M.L., Convirs-Fowler, Coyner, Fowler, Helmer, Heretick, Hope, Keam, Kory, Levine, Mugler, Plum, Ransone, Reid, Samirah, Scott, Simon, Simonds, Sullivan and Ware; Senators: Bell, Boysko, Hashmi, Howell and Spruill

Referred to Committee on Rules

WHEREAS, cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 children and adults in the United States, with approximately 800 Virginians currently living with cystic fibrosis; and

WHEREAS, cystic fibrosis is caused by a defective gene that makes the body produce unusually thick, sticky mucus that clogs the lungs, pancreas, and other parts of the body, making it extremely difficult for people with the condition to breathe and leading to life-threatening infections; and

WHEREAS, thanks in large part to the Cystic Fibrosis Foundation, 14 cystic fibrosis therapies have been approved and are in use by patients, four of which target the underlying cause of the disease; and

WHEREAS, approximately seven percent of people with cystic fibrosis have two "nonsense" or rare mutations, meaning they will not benefit solely from treatment with a modulator that treats the underlying cause of the disease; and

WHEREAS, through the Cystic Fibrosis Foundation's efforts and with the support of research, drug developments, and specialized care, the life expectancy of a child with cystic fibrosis has doubled in the last 30 years, making median life expectancy now 44 years old; and

WHEREAS, there are eight accredited cystic fibrosis care centers in the Commonwealth, including adult and pediatric programs; 42 percent of children and 20 percent of adults with cystic fibrosis in the Commonwealth rely on Medicaid to cover treatment; and

WHEREAS, since 2014, the Cystic Fibrosis Foundation has provided more than \$6 million in grants for research conducted in the Commonwealth; and

WHEREAS, the Virginia Chapter of the Cystic Fibrosis Foundation was established in 1992, and since 2000, the Chapter has contributed approximately \$26.7 million to help support the fight against cystic fibrosis through fundraising events, campaigns, and initiatives, such as Great Strides, Starry Night Chefs Event, Virginia's Finest Young Professionals, and Xtreme Hike; and

WHEREAS, the Virginia Chapter of the Cystic Fibrosis Foundation has a board of directors in Richmond, a board of directors in Hampton Roads, and a Young Professional Leadership Council that help oversee fundraising, advocacy, outreach, and volunteer engagement efforts; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the General Assembly designate May, in 2021 and in each succeeding year, as Cystic Fibrosis Awareness Month in Virginia; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates transmit a copy of this resolution to the Virginia Chapter of the Cystic Fibrosis Foundation so that members of the organization may be apprised of the sense of the General Assembly of Virginia in this matter; and, be it

RESOLVED FINALLY, That the Clerk of the House of Delegates post the designation of this month on the General Assembly's website.

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