

## 2019-J1399

Senate Resolution No. 1399

BY: Senator AMEDORE

MEMORIALIZING Governor Andrew M. Cuomo to proclaim May 2019, as Cystic Fibrosis Awareness Month in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official months that are set aside to increase awareness of serious illnesses that affect the lives of citizens of New York State; and

WHEREAS, Attendant to such concern, and in full accord with its long-standing traditions, this Legislative Body is justly proud to memorialize Governor Andrew M. Cuomo to proclaim May 2019, as Cystic Fibrosis Awareness Month in the State of New York; and

WHEREAS, The Cystic Fibrosis Foundation, a donor-supported nonprofit organization, is the world's leader in the search for a cure for cystic fibrosis, having raised and invested hundreds of millions of dollars to help develop drugs and therapies; and

WHEREAS, The Cystic Fibrosis Foundation is working to cure cystic fibrosis and to provide all people struggling with the disease the opportunity to lead full, productive lives; and

WHEREAS, Cystic fibrosis, commonly referred to as "CF", is a genetic disease affecting more than 30,000 children and adults in the United States, and 70,000 children and adults worldwide, 1,650 of whom live in New York; and

WHEREAS, A defective gene causes the body to produce an abnormally thick, sticky mucus that clogs the lungs, and these secretions produce

life-threatening lung infections and obstruct the pancreas, preventing digestive enzymes from reaching the intestines to help break down and absorb food; and

WHEREAS, More than 10 million Americans are symptomless carriers of the defective CF gene, and CF occurs in approximately one of every 3,500 live births in the United States, making it the most common generic disease in the U.S.; and

WHEREAS, The median age of survival for a person with CF is 47.7 years; and

WHEREAS, With advances in the treatment of CF, the number of adults with CF has steadily grown, and approximately 1,000 new cases of CF are diagnosed each year; and

WHEREAS, Through the CF Foundation's efforts and care centers in New York, the life expectancy of a child with CF has doubled in the last 30 years, and research to find a cure is more promising than ever; and

WHEREAS, More than 75% of people are diagnosed by age 2, more than 50% of the CF population is 18 years of age and older, and people with CF have a variety of symptoms attributed to the more than 1,800 mutations of the CF gene; and

WHEREAS, Infant blood screening to detect genetic defects is the most reliable and least costly method to identify persons likely to have CF; and

WHEREAS, Early diagnosis of CF permits early treatment and enhances quality of life and longevity and the treatment of CF depends on the stage of the disease and the organs involved; and

WHEREAS, Clearing mucus from the lungs is an important part of the daily CF treatment regimen, and other types of treatments include inhaled antibiotics and pancreatic enzymes, among others; and

WHEREAS, There are 23 accredited CF treatment centers in New York, which specialize in the diagnosis of CF and the care of persons with CF; and

WHEREAS, It is imperative that there be greater public awareness of this serious health issue, and more must be done to increase activity at the local, State and national levels; and

WHEREAS, This Legislative Body commends the dedication of those working to improve the quality of life of individuals with CF, families of those individuals and the 66 thousand CF advocates in the great State of New York, and expresses continued support for accelerated research to develop more effective treatments for Cystic Fibrosis and to ultimately find a cure; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim May 2019, as Cystic Fibrosis Awareness Month in the State of New York; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Andrew M. Cuomo, Governor of the State of New York.