Assembly Resolution No. 2147

BY: M. of A. Rules (Jones)

MEMORIALIZING Governor Kathy Hochul to proclaim May 2024, 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 Kathy Hochul to proclaim May 2024, as Cystic Fibrosis Awareness Month in the State of New York, in conjunction with the observance of National Cystic Fibrosis Month; 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 approximately 40,000 children and adults in the United States and more than 105,000 children and adults worldwide, over 1,600 of whom live in New York; furthermore, approximately 1,000 new cases are diagnosed each year; 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

WHEREAS, The median predicted age of survival for a person with CF, born in 2019, is 48.4 years; and

WHEREAS, With advances in the treatment of CF, the number of adults with CF has steadily grown, and approximately 900 new cases of CF are diagnosed each year; and

WHEREAS, 56% 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 2,000 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 21 world-class treatment centers in New York which specialize in the diagnosis of CF and the care of persons with CF; and

WHEREAS, A critical component of treating patients with CF includes access to innovative treatments, which can play a crucial role in the lives of patients with CF; and

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

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim May 2024, 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 Kathy Hochul, Governor of the State of New York.