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## SCR-103 Cystic Fibrosis Awareness Month. (2021-2022)

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### Senate Concurrent Resolution No. 103

#### CHAPTER 90

Relative to Cystic Fibrosis Awareness Month.

[ Filed with Secretary of State June 24, 2022. ]

#### LEGISLATIVE COUNSEL'S DIGEST

SCR 103, Pan. Cystic Fibrosis Awareness Month.

This measure would proclaim the month of May 2022 as Cystic Fibrosis Awareness Month.

Fiscal Committee: no

WHEREAS, Cystic fibrosis, a chronic and progressive systemic disease for which there is no known cure, is the most common fatal genetic disease in the United States; and

WHEREAS, Nearly 31,000 children and adults in the United States have been diagnosed with cystic fibrosis, and more than 1,000 new cases are diagnosed each year, predominantly through newborn screening; and

WHEREAS, Due to progress in understanding the disease and new therapeutic advances, the average life expectancy for an individual recently diagnosed with cystic fibrosis is in the mid-40s; and

WHEREAS, Despite advances in disease understanding and new therapies, the median age of death for those with cystic fibrosis is 34 years of age; and

WHEREAS, Cystic fibrosis impacts individuals of every race and ethnicity, but due to health disparities and newborn screening panels that fail to capture rare cystic fibrosis transmembrane conductance regulator (CFTR) mutations, many individuals with cystic fibrosis are misdiagnosed or diagnosed late; and

WHEREAS, The federal Centers for Disease Control and Prevention estimates that more than 12 million Americans are unknowing, symptomless carriers of the cystic fibrosis gene and have high odds of passing the gene to their children; and

WHEREAS, Prompt, aggressive treatment of the symptoms of cystic fibrosis can extend the lives of people who have the disease; and

WHEREAS, Recent advances in cystic fibrosis research have produced promising leads in gene, protein, and drug therapies beneficial to people who have the disease; and

WHEREAS, Cystic fibrosis research continues for potential therapies, and a nationwide network of care centers exists to improve the length and quality of life for individuals with cystic fibrosis; however, lives continue to be lost to this disease; and

WHEREAS, The Cystic Fibrosis Research Institute (CFRI) was formed in 1975 with a mission to be a global resource for the cystic fibrosis community while pursuing a cure through research, education, advocacy, and support; and

WHEREAS, The CFRI provides funding for innovative cystic fibrosis research at medical and academic centers nationwide to expand understanding of the disease process and to seek new therapies and ultimately a cure for this challenging multisystemic disease; and

WHEREAS, The CFRI seeks to improve the quality of life for all people with cystic fibrosis in California and the nation, as well as their family members, by providing psychosocial support programs; and

WHEREAS, Education of the public about cystic fibrosis, including the symptoms of the disease and its impact upon people of all races and ethnicities, increases knowledge and understanding of cystic fibrosis and promotes early diagnosis, and the CFRI serves as a vital link in providing vital educational resources; and

WHEREAS, Support for those impacted by cystic fibrosis, a rare disease, begins with the raising of public awareness, and the CFRI works within the diverse cystic fibrosis community on both the state and national level to advocate for continued research, access to quality care, and the development of new therapies to extend and enhance lives; now, therefore, be it

Resolved by the Senate of the State of California, the Assembly thereof concurring, That the Legislature proclaims the month of May 2022 as Cystic Fibrosis Awareness Month; and be it further

Resolved, That the Legislature honors the goals and ideals of Cystic Fibrosis Awareness Month so as to promote public awareness and understanding of cystic fibrosis and the diverse communities it impacts; and be it further

Resolved, That the Legislature encourages early diagnosis and access to quality care for all people with cystic fibrosis to improve the quality of their lives, advocates for increased support for people who have cystic fibrosis and their families, and supports research to find a cure for cystic fibrosis; and be it further

Resolved, That the Secretary of the Senate transmit copies of this resolution to the author for appropriate distribution.