

DRAFT

SUMMARY

Designates May of each year as Cystic Fibrosis Awareness Month.
Declares emergency, effective on passage.

A BILL FOR AN ACT

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Relating to a month to raise awareness for cystic fibrosis; and declaring an emergency.

Whereas cystic fibrosis, commonly referred to as “CF,” is a genetic disease affecting approximately 30,000 children and adults in the United States, nearly 400 of whom live in Oregon, and nearly 70,000 children and adults worldwide; and

Whereas CF is the result of a defective gene that causes the body to produce an abnormally thick, sticky mucus that clogs the lungs, resulting in life-threatening lung infections, and secretions that 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 out of every 3,500 infants born in the United States; and

Whereas the median age of survival for a person with CF is 41.1 years; and

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

Whereas nearly 50 percent of the diagnosed CF population is 18 years of

NOTE: Matter in **boldfaced** type in an amended section is new; matter [*italic and bracketed*] is existing law to be omitted. New sections are in **boldfaced** type.

1 age or older; and

2 Whereas persons with CF have a variety of symptoms attributed to the
3 more than 1,800 mutations of the CF gene; and

4 Whereas infant blood screening to detect genetic defects is the most re-
5 liable and least costly method to identify persons likely to have CF; and

6 Whereas early diagnosis of CF permits early treatment and can enhance
7 quality of life and longevity, and successful treatment of CF depends on the
8 stage of the disease and the organs involved; and

9 Whereas clearing mucus from the lungs is an important part of the daily
10 CF treatment regimen, and other types of treatments include inhaled antibi-
11 otics and pancreatic enzymes; and

12 Whereas there are two world-class treatment centers in Oregon that spe-
13 cialize in the diagnosis of CF and the care of persons with CF; and

14 Whereas a critical component of treating patients with CF is access to
15 innovative treatments, which can play a crucial role in the lives of patients
16 with CF; and

17 Whereas improving longevity and quality of life for people with CF starts
18 with awareness; now, therefore,

19 **Be It Enacted by the People of the State of Oregon:**

20 **SECTION 1. May of each year is designated as Cystic Fibrosis**
21 **Awareness Month.**

22 **SECTION 2. This 2016 Act being necessary for the immediate pres-**
23 **ervation of the public peace, health and safety, an emergency is de-**
24 **clared to exist, and this 2016 Act takes effect on its passage.**

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