

# Senate Bill 1522

Sponsored by Senator COURTNEY (Presession filed.)

## SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure **as introduced**.

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

## A BILL FOR AN ACT

1  
2 Relating to a month to raise awareness for cystic fibrosis; and declaring an emergency.

3       Whereas cystic fibrosis, commonly referred to as "CF," is a genetic disease affecting approxi-  
4 mately 30,000 children and adults in the United States, nearly 400 of whom live in Oregon, and  
5 nearly 70,000 children and adults worldwide; and

6       Whereas CF is the result of a defective gene that causes the body to produce an abnormally  
7 thick, sticky mucus that clogs the lungs, resulting in life-threatening lung infections, and secretions  
8 that obstruct the pancreas, preventing digestive enzymes from reaching the intestines to help break  
9 down and absorb food; and

10       Whereas more than 10 million Americans are symptomless carriers of the defective CF gene, and  
11 CF occurs in approximately one out of every 3,500 infants born in the United States; and

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

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

15       Whereas nearly 50 percent of the diagnosed CF population is 18 years of age or older; and

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

18       Whereas infant blood screening to detect genetic defects is the most reliable and least costly  
19 method to identify persons likely to have CF; and

20       Whereas early diagnosis of CF permits early treatment and can enhance quality of life and  
21 longevity, and successful treatment of CF depends on the stage of the disease and the organs in-  
22 volved; and

23       Whereas clearing mucus from the lungs is an important part of the daily CF treatment regimen,  
24 and other types of treatments include inhaled antibiotics and pancreatic enzymes; and

25       Whereas there are two world-class treatment centers in Oregon that specialize in the diagnosis  
26 of CF and the care of persons with CF; and

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

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

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

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

2        **SECTION 2. This 2016 Act being necessary for the immediate preservation of the public**  
3 **peace, health and safety, an emergency is declared to exist, and this 2016 Act takes effect**  
4 **on its passage.**

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