

**Fiscal:** No fiscal impact

**Revenue:** No Revenue Impact

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**Action Date:** 02/24/16

**Action:** Do Pass.

**Meeting Dates:** 02/24

**Vote:**

Yeas: 9 - Barnhart, Gilliam, Hoyle, Huffman, Kennemer, Rayfield, Smith Warner, Williamson, Wilson

**Prepared By:** Erin Seiler, Committee Administrator

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**WHAT THE MEASURE DOES:**

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

**ISSUES DISCUSSED:**

- Importance of increasing awareness of cystic fibrosis (CF)
- Impact of CF on patients and families
- Improvements in research, treatments and quality of life for patients

**EFFECT OF COMMITTEE AMENDMENT:**

No amendment.

**BACKGROUND:**

Cystic fibrosis (CF) affects 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. It is estimated that 1,000 new cases are diagnosed each year and the disease occurs in approximately one out of every 3,500 infants born in the U.S.

CF is a life-threatening, genetic disease that causes persistent lung infections and progressively limits the ability to breathe. In people with CF, a defective gene causes a buildup of mucus in the lungs, pancreas and other organs. In the lungs, the airways become clogged and trap bacteria leading to infections, extensive lung damage and eventually, respiratory failure.

An increase in research has led to advances in screening, early diagnosis and early treatment interventions for patients. As CF used to be considered exclusively a childhood disease, people with the disease are living into their 30s, 40s and beyond with the life expectancy for someone with CF being an average of 41 years.

May is recognized, nationally, as Cystic Fibrosis Awareness Month, in order to bring together volunteers to raise awareness, raise funds, and advocate for more research. Senate Bill 1522 designates May of each year as Cystic Fibrosis Awareness Month.