



Megan Byrnett

## *Bill Analysis*

*Legislative Service Commission*

### **H.B. 549**

125th General Assembly  
(As Introduced)

**Reps. Fessler, Clancy, Trakas, Schaffer, Hoops, Schmidt, Kearns, McGregor, Hollister, Reidelbach, Wagner, Carano, S. Smith, Skindell, Miller, Allen, Yates, Brown, Ujvagi, Perry, Barrett, Redfern**

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### **BILL SUMMARY**

- Creates the Cystic Fibrosis Advisory Council to advise the Director of Health about issues related to the care and treatment of individuals with cystic fibrosis.

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### **CONTENT AND OPERATION**

#### **Cystic Fibrosis Advisory Council**

(R.C. 3701.93)

The bill creates the Cystic Fibrosis Advisory Council in the Department of Health. The Council is to advise the Director of Health on issues pertaining to the care and treatment of individuals with cystic fibrosis, including the use of prescription drug and innovative therapies.

#### **Council members**

The bill provides for the Council to have 11 members. The Speaker of the House of Representatives, President of the Senate, and the Governor are each to appoint three members. At least two of the members appointed by the Speaker and at least two of the members appointed by the Senate President must have been diagnosed with cystic fibrosis or be relatives<sup>1</sup> of such individuals. At least one of the members appointed by the Governor must have been diagnosed with cystic fibrosis or be a relative of such an individual. The remaining two members are the chairs of the House and Senate committees dealing primarily with health issues, or

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<sup>1</sup> The bill defines "relative" as a spouse, parent, parent-in-law, sibling, sibling-in-law, child, child-in-law, grandparent, aunt, or uncle.

the chairs' designees. Each member has the authority to vote on matters before the Council.

### **Council members' terms and procedures**

The initial Council members must be appointed within 90 days after the bill's effective date. Each member is to serve a two-year term that ends on the same day of the same month as did the term it succeeds. Members may continue on the Council until a successor takes office or until a period of 60 days has elapsed, whichever occurs first. Vacancies are filled in the same manner as original appointments. A member appointed to fill a vacancy prior to the expiration date of the term for which the member's predecessor was appointed may hold office for the remainder of that term. Members may be reappointed to the Council.

The Council is required to elect a chair to serve for two years. A majority of members of the Council constitutes a quorum for the purpose of conducting Council meetings. A vacancy of the chair position must be filled by election.

Members of the Council are not to be compensated. The Council may, however, solicit grants from public or private sources to reimburse members for expenses incurred in performing their duties and to pursue initiatives related to the care and treatment of individuals with cystic fibrosis. The Department of Health is required to provide the Council meeting space and clerical and technical assistance.

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## **COMMENT**

Cystic fibrosis is a genetic disease that causes the body to produce abnormal mucus that can block pathways to the lungs and lead to severe lung infections. Symptoms of cystic fibrosis include salty skin, persistent coughing, wheezing, shortness of breath, abnormal appetites, and gastrointestinal problems. Adults living with cystic fibrosis are likely to be sterile or unable to carry a baby to term due to the effects of cystic fibrosis. Adults with cystic fibrosis may also suffer from diabetes or osteoporosis related to cystic fibrosis.

Cystic fibrosis is caused by a genetic defect--when both parents carry the defective gene, there is a 25% chance that their child will develop cystic fibrosis. It is estimated that 10 million Americans carry the gene that causes cystic fibrosis, but do not suffer from cystic fibrosis themselves. Approximately 1,000 new cases of cystic fibrosis are diagnosed in the United States each year.

There are several forms of treatment for cystic fibrosis. The primary goal is to keep the lungs clear of the abnormal mucus that leads to infection. This may be

done through simple means, such as clapping the back to clear the lungs, or through more complicated techniques, including the use of antibiotics and other drugs to keep the lungs clear. The expected lifespan for individuals with cystic fibrosis varies, but the median age of survival is 33. With newer treatments, the lifespan has increased dramatically; now 40% of individuals living with cystic fibrosis are adults.<sup>2</sup>

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## HISTORY

ACTION	DATE	JOURNAL ENTRY
Introduced	09-14-04	p. 2158

H0549-I-125.doc/jc

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<sup>2</sup> *The Cystic Fibrosis Foundation, [www.cff.org](http://www.cff.org) (last visited 10/20/04).*

