

SENATE BILL REPORT

SB 5864

As of January 12, 2024

Title: An act relating to establishing a point of contact for any person diagnosed with a rare disease.

Brief Description: Establishing a point of contact for any person diagnosed with a rare disease.

Sponsors: Senator Fortunato.

Brief History:

Committee Activity: Health & Long Term Care: 1/12/24.

Brief Summary of Bill

- Establishes a point of contact at the Health Care Authority for people diagnosed with a rare disease who are seeking assistance through any of the agency's programs.

SENATE COMMITTEE ON HEALTH & LONG TERM CARE

Staff: Julie Tran (786-7283)

Background: Rare Diseases. The United States Congress, in the Orphan Drug Act of 1983, defines a rare disease as a disease that affects fewer than 200,000 people in the United States. Rare diseases include genetic conditions, infections, some rare cancers, and autoimmune diseases. The National Institutes of Health estimates there are over 10,000 known rare diseases and, in the United States, rare diseases affect about 25 to 30 million Americans.

Health Care Authority. The Washington State Health Care Authority (HCA) is an executive branch agency led by a director appointed by the Governor. HCA's primary duties relate to the administration of insurance benefits for state and school employees, retirees, and their dependents; administering medical assistance programs for eligible low-income residents;

This analysis was prepared by non-partisan legislative staff for the use of legislative members in their deliberations. This analysis is not part of the legislation nor does it constitute a statement of legislative intent.

and overseeing cost-containment initiatives in state-purchased health care.

Summary of Bill: The HCA Director shall establish a single point of contact at HCA to provide support to any person diagnosed with a rare disease who is seeking assistance through any of the programs administered by HCA.

Appropriation: None.

Fiscal Note: Requested on December 28, 2023.

Creates Committee/Commission/Task Force that includes Legislative members: No.

Effective Date: Ninety days after adjournment of session in which bill is passed.

Staff Summary of Public Testimony: PRO: This is a good little bill inspired by my grandson, who has a rare disease. There is a lack of understanding about the special conditions that rare diseases may have. Families and individuals with rare diseases have trouble navigating the programs, services, and resources that are available. The purpose of the bill is to have somebody that understands rare diseases and has some experience to assist these individuals. This also connects to issues with caregiver hours and the need for more hours as rare diseases is not something that is typically dealt with.

Persons Testifying: PRO: Senator Phil Fortunato, Prime Sponsor.

Persons Signed In To Testify But Not Testifying: No one.