

Individual State Agency Fiscal Note

Bill Number: 5864 SB	Title: Rare disease contact	Agency: 107-Washington State Health Care Authority
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Part I: Estimates

No Fiscal Impact

Estimated Cash Receipts to:

NONE

Estimated Operating Expenditures from:

Non-zero but indeterminate cost and/or savings. Please see discussion.

Estimated Capital Budget Impact:

NONE

The cash receipts and expenditure estimates on this page represent the most likely fiscal impact. Factors impacting the precision of these estimates, and alternate ranges (if appropriate), are explained in Part II.

Check applicable boxes and follow corresponding instructions:

- If fiscal impact is greater than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete entire fiscal note form Parts I-V.
- If fiscal impact is less than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete this page only (Part I).
- Capital budget impact, complete Part IV.
- Requires new rule making, complete Part V.

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Part II: Narrative Explanation

II. A - Brief Description Of What The Measure Does That Has Fiscal Impact

Significant provisions of the bill and any related workload or policy assumptions that have revenue or expenditure impact on the responding agency by section number.

See attached.

II. B - Cash receipts Impact

Cash receipts impact of the legislation on the responding agency with the cash receipts provisions identified by section number and when appropriate, the detail of the revenue sources. Description of the factual basis of the assumptions and the method by which the cash receipts impact is derived. Explanation of how workload assumptions translate into estimates. Distinguished between one time and ongoing functions.

II. C - Expenditures

Agency expenditures necessary to implement this legislation (or savings resulting from this legislation), with the provisions of the legislation that result in the expenditures (or savings) identified by section number. Description of the factual basis of the assumptions and the method by which the expenditure impact is derived. Explanation of how workload assumptions translate into cost estimates. Distinguished between one time and ongoing functions.

Part III: Expenditure Detail

III. A - Operating Budget Expenditures

Non-zero but indeterminate cost and/or savings. Please see discussion.

III. B - Expenditures by Object Or Purpose

Non-zero but indeterminate cost and/or savings. Please see discussion.

III. C - Operating FTE Detail: *FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part I and Part IIIA.*

NONE

III. D - Expenditures By Program (optional)

NONE

Part IV: Capital Budget Impact

IV. A - Capital Budget Expenditures

NONE

IV. B - Expenditures by Object Or Purpose

NONE

IV. C - Capital Budget Breakout

Acquisition and construction costs not reflected elsewhere on the fiscal note and description of potential financing methods.

NONE

IV. D - Capital FTE Detail: *FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part IVB.*

NONE

Part V: New Rule Making Required

Provisions of the bill that require the agency to adopt new administrative rules or repeal/revise existing rules.

HCA Fiscal Note

Bill Number: **5864 SB**

HCA Request #: 24-004

Title: **Rare Disease Contact**

Part I: Estimates

No Fiscal Impact

Estimated Cash Receipts to:

NONE

Estimated Operating Expenditures from:

NONE

Estimated Capital Budget Impact:

NONE

The cash receipts and expenditure estimates on this page represent the most likely fiscal impact. Factors impacting the precision of these estimates, and alternate ranges (if appropriate), are explained in Part II.

Check applicable boxes and follow corresponding instructions:

- If fiscal impact is greater than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete entire fiscal note form Parts I-V.
- If fiscal impact is less than \$50,000 per fiscal year in the current biennium or in subsequent biennia, complete this page only (Part I).
- Capital budget impact, complete Part IV.
- Requires new rule making, complete Part V.

HCA Fiscal Note

Bill Number: **5864 SB**

HCA Request #: 24-004

Title: **Rare Disease Contact**

Part II: Narrative Explanation

II. A - Brief Description Of What The Measure Does That Has Fiscal Impact

Significant provisions of the bill and any related workload or policy assumptions that have revenue or expenditure impact on the responding agency by section number.

AN ACT Relating to establishing a point of contact for any person diagnosed with a rare disease; and adding a new section to chapter 41.05 RCW.

NEW Section 1

(1) The Health Care Authority (HCA) Director shall establish a single point of contact to provide support to any person diagnosed with a rare disease who is seeking assistance through any of the programs administered by HCA.

(2) For the purpose of this section, "rare disease" means a disease that affects fewer than 200,000 people in the United States of America (USA).

II. B - Cash Receipts Impact

Cash receipts impact of the legislation on the responding agency with the cash receipts provisions identified by section number and when appropriate, the detail of the revenue sources. Description of the factual basis of the assumptions and the method by which the cash receipts impact is derived. Explanation of how workload assumptions translate into estimates. Distinguish between one time and ongoing functions.

NONE

II. C - Expenditures

Agency expenditures necessary to implement this legislation (or savings resulting from this legislation), with the provisions of the legislation that result in the expenditures (or savings) identified by section number. Description of the factual basis of the assumptions and the method by which the expenditure impact is derived. Explanation of how workload assumptions translate into cost estimates. Distinguish between one time and ongoing functions.

Indeterminate fiscal impact.

This bill establishes a single point of contact for any person diagnosed with a rare disease. It is assumed the costs to HCA could be between \$1,875,000 to \$31,000,000 in General Fund State annually for staffing alone to create a single point of contact.

Section 1 (2) is only a definition of a rare disease. This definition aligns with the National Institutes of Health (NIH)'s definition. The NIH estimates that there are 25-30 million Americans living with a rare

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Bill Number: **5864 SB**

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Title: **Rare Disease Contact**

disease with over 7,000 different types of rare diseases that affects fewer than 200,000 people for each disease.

Assuming that HCA serves around 2-3 million Washingtonians, and a similar proportion (to the national population) have rare diseases. Over 750,000 people are estimated to have a rare disease in Washington.

This could potentially be a huge population of people to serve with a “single point of contact”. HCA Fee For Service (FFS) may require a significant number of additional staff (up to a minimum of 16 full time equivalent FTE and a potential maximum of 250 FTEs) to support care coordination unless contracted out through a third-party vendor, resulting in procurement needs and continued funding for maintenance of the program.

This bill revises RCW 41.05 and directs activity through any of the programs administered by HCA, encompassing the School Employees Benefits Board (SEBB), Public Employees Benefits Board (PEBB), Medicaid Apple Health, and behavioral health programs for all state residents.

Part III: Expenditure Detail

III. A - Operating Budget Expenditure

NONE

III. B - Expenditures by Object Or Purpose

NONE

III. C - Operating FTE Detail: FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part I and Part IIIA.

NONE

III. D - Expenditures By Program (optional)

NONE

Part IV: Capital Budget Impact

IV. A - Capital Budget Expenditures

NONE

IV. B - Expenditures by Object Or Purpose

NONE

HCA Fiscal Note

Bill Number: **5864 SB**

HCA Request #: 24-004

Title: **Rare Disease Contact**

IV. C - Capital Budget Breakout: Acquisition and construction costs not reflected elsewhere on the fiscal note and description of potential financing methods.

NONE

IV. D - Capital FTE Detail: FTEs listed by classification and corresponding annual compensation. Totals agree with total FTEs in Part IVB.

NONE

Part V: New Rule Making Required

Provisions of the bill that require the agency to adopt new administrative rules or repeal/revise existing rules.

NONE