

# Multiple Agency Fiscal Note Summary

<b>Bill Number:</b> 5097 SB	<b>Title:</b> Rare diseases adv. council
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## Estimated Cash Receipts

NONE

## Estimated Operating Expenditures

Agency Name	2023-25				2025-27				2027-29			
	FTEs	GF-State	NGF-Outlook	Total	FTEs	GF-State	NGF-Outlook	Total	FTEs	GF-State	NGF-Outlook	Total
Washington State Health Care Authority	.0	0	0	0	.0	0	0	0	.0	0	0	0
Department of Health	10.4	5,216,000	5,216,000	5,216,000	9.9	4,836,000	4,836,000	4,836,000	9.9	4,836,000	4,836,000	4,836,000
<b>Total \$</b>	<b>10.4</b>	<b>5,216,000</b>	<b>5,216,000</b>	<b>5,216,000</b>	<b>9.9</b>	<b>4,836,000</b>	<b>4,836,000</b>	<b>4,836,000</b>	<b>9.9</b>	<b>4,836,000</b>	<b>4,836,000</b>	<b>4,836,000</b>

## Estimated Capital Budget Expenditures

Agency Name	2023-25			2025-27			2027-29		
	FTEs	Bonds	Total	FTEs	Bonds	Total	FTEs	Bonds	Total
Washington State Health Care Authority	.0	0	0	.0	0	0	.0	0	0
Department of Health	.0	0	0	.0	0	0	.0	0	0
<b>Total \$</b>	<b>0.0</b>	<b>0</b>	<b>0</b>	<b>0.0</b>	<b>0</b>	<b>0</b>	<b>0.0</b>	<b>0</b>	<b>0</b>

## Estimated Capital Budget Breakout

<b>Prepared by:</b> Breann Boggs, OFM	<b>Phone:</b> (360) 485-5716	<b>Date Published:</b> Final
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# Individual State Agency Fiscal Note

<b>Bill Number:</b> 5097 SB	<b>Title:</b> Rare diseases adv. council	<b>Agency:</b> 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:**

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.

Legislative Contact: Andie Parnell	Phone: 3607867439	Date: 01/10/2023
Agency Preparation: Melinda Helberg	Phone: 360-725-0000	Date: 01/13/2023
Agency Approval: SUMAN MAJUMDAR	Phone: 360-725-1319	Date: 01/13/2023
OFM Review: Jason Brown	Phone: (360) 742-7277	Date: 01/13/2023

## 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 narrative.

### 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.*

See attached narrative.

### 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.*

See attached narrative.

## Part III: Expenditure Detail

### III. A - Operating Budget Expenditures

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

### 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: 5097 SB

HCA Request #: 23-017

## **Part II: Narrative Explanation**

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

An act relating to creating an advisory council on rare diseases; adding new sections to chapter 43.70 RCW; and creating a new section.

Section 3: A new section added to chapter 43.70 RCW to (1) establish an advisory council on rare diseases to advise the governor, state agencies, and the legislature on research, diagnosis, treatment, and education related to rare diseases. (2) The secretary shall appoint 12 voting members to the council who will serve a three-year term to include a representative from the Washington State Health Care Authority (HCA).

### **II. B - Cash Receipts Impact**

None

### **II. C – Expenditures**

No fiscal impact.

HCA involvement is for a representative participating on Department of Health's Advisory Council on Rare diseases. Participation on the board can be absorbed by existing staff.

## **Part IV: Capital Budget Impact**

None

## **Part V: New Rule Making Required**

None

# Individual State Agency Fiscal Note

<b>Bill Number:</b> 5097 SB	<b>Title:</b> Rare diseases adv. council	<b>Agency:</b> 303-Department of Health
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## Part I: Estimates

No Fiscal Impact

### Estimated Cash Receipts to:

NONE

### Estimated Operating Expenditures from:

	FY 2024	FY 2025	2023-25	2025-27	2027-29
FTE Staff Years	10.8	9.9	10.4	9.9	9.9
<b>Account</b>					
General Fund-State      001-1	2,798,000	2,418,000	5,216,000	4,836,000	4,836,000
<b>Total \$</b>	2,798,000	2,418,000	5,216,000	4,836,000	4,836,000

### 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.

Legislative Contact: Andie Parnell	Phone: 3607867439	Date: 01/10/2023
Agency Preparation: Sharilynn Boelk	Phone: 3602363000	Date: 01/23/2023
Agency Approval: Kristin Bettridge	Phone: 3607911657	Date: 01/23/2023
OFM Review: Breann Boggs	Phone: (360) 485-5716	Date: 01/25/2023

## 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.*

Section 3: States that the Department of Health (department) shall provide staff support to the 12-person council for rare diseases (council). The council will meet no later than 3 months after the effective date of this section and shall meet at the call of the chair or upon the request of a majority of councilmembers for future meetings. Travel expenses are to be reimbursed to councilmembers as well. The council may receive gifts, grants, or endowments from public or private sources.

Section 4: States that by July 1, 2026, the council shall establish a centralized publicly accessible repository of information on best practices of care with health care providers and catalogue rare disease research ongoing. Also beginning December 1, 2026, the council is to submit a report to the governor and the legislature detailing their work for the preceding year, identifying opportunities to support programs that directly impact the lives of patients with rare diseases and providing recommendations for statutory changes to the structure and duties of the council.

### 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.*

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. Distinguished between one time and ongoing functions.*

#### Section 3 - Support Council and Equitable Participation

This bill requires the department to create an advisory council on rare diseases as established within the department to advise the governor, state agencies, and the legislature on research, diagnosis, treatment, and education related to rare diseases. The department must provide staff support for the council. Requires travel expenses to be reimbursed for councilmembers. The department assumes council members will be compensated for their participation on the council.

#### Section Cost Estimates:

FY24 = 5.3 FTE and \$1,128,000

FY25 and ongoing = 4.9 FTE and \$934,000

0.3 FTE ongoing Public Health and Epidemiologist 3 will be the project manager who will lead the project team and direct the collaborative work of Health Services Consultants. This position will also oversee managing the program budget and coordinating with contractor providing technical assistance.

0.5 FTE ongoing Health Services Consultant 4 - Policy Analyst will be responsible for supporting the agency in appointment of the council, communications with policy makers and the Governor's office regarding rare disease advisory requests, and facilitation of advisory council meetings and support of stakeholder partnerships, including engagement with tribes, local health jurisdictions, or other community entities. This position will also manages drafting and submission of the biennial report to the legislature. Historical experience identified this role need.

1.0 FTE ongoing Health Services Consultant 3 – program and communication staff will be responsible for communications to promote public awareness and education. They will lead any tribal and community engagement and integrate social

determinants of health and health equity into the council's partnerships, planning, and policy development. This position will be the point person for supporting the council's advisory work and lead coordinating the advisory council meetings and compensation process.

1.0 FTE ongoing Health Services Consultant 2 will be responsible for planning meetings, member engagement, and logistics support for council meetings. They will develop and manage logistical plans for council meetings. They will attend and participate in council meetings to provide technology assistance, note taking, and meeting coordination support. They will be responsible for managing communication activities for the advisory council before and after council meetings and ensure communication materials are up to date. They will assist to orient new members of the council while providing individualized member support (e.g., sending reminders about upcoming meeting, preparing presentations or informational materials for members to share with their constituencies, scheduling one-on-one meetings, tracking member terms, etc.), and complete short-term projects and assignments as assigned by the advisory council.

0.2 FTE for FY24 and 0.1 FTE ongoing WMS02 – Manager provides leadership and direction to project staff within the framework of the agency, division, and office strategic plans and coordinates council work with other agency goals and activities. This position also supervises program staff supporting the council.

0.1 FTE ongoing Administrative Assistant 3 will support procuring needed goods and services, facilitating member, staff compensation and travel reimbursement, and assisting with planning meeting logistics.

0.2 FTE ongoing Budget Analyst 3 responsible for building, monitoring program budget, providing contract support, process community compensation, tracking compensation, and fiscal review.

Community Compensation: \$12,080 FY24 and ongoing

Section 3 directs the Department of Health to complete Rare Diseases adv. Council. In compliance with RCW 43.03.220, Compensation of Members of Part-Time Boards and Commissions – Class one groups, this bill would require compensation of community members with lived experience and/or those living in poverty. All community engagement activities at DOH must be in compliance with Title II of the Americans with Disabilities Act, the Heal Act Community Engagement Guide, and possibly the Open Public Meeting Act. In addition to the cost of compensation, observance of these statutory obligations includes providing reimbursement for travel, lodging, and dependent care; translation and interpretation services for all meetings and materials; and the staffing to support managing resources and associated program activities.

The advisory committee members who are not otherwise compensated for their time serving on the committee will receive compensation. Based on similar projects, department assumes 10 members requesting compensation at \$35/hour of meeting, with 12 meetings each year (10 one-hour virtual meetings and 2 three-hour in-person), for a total of \$5,600/year. Estimate that potentially 4 committee members will need support for possible dependent care at \$100/meeting for a total of \$4,800/year. \$1,680 for 4 members compensation for travel time at \$35 per hour for 6 hours for 2 meetings.

Travel Reimbursement - \$4,038/year ongoing

Assuming two of the meetings will be done in-person, 8 of the councilmembers will be local, and 4 would require airfare from Spokane to Seattle. For the 8 local council member's travel to meeting, assume an average roundtrip of 80 miles at the \$0.655/mile reimbursement rate for 2 in-person meetings. Local travel cost for these 8 council members would be \$838 per year. For the 4 out-of-town council members travel to meetings, assume \$280 roundtrip airfare and \$120 for transit/parking for 4 members for 2 meetings. Out-of-town travel cost for these 4 council members would be \$3,200 per year. Local travel cost of \$834 + out-of-town travel of \$3,200 = \$4,034.

Personal Service Contracts – Plan to contract \$75,000 with an organization that specializes in medical genetics/rare diseases for technical assistance, information gathering, and analysis. Meeting with partners and key informants to understand relevant issues. Conducting ongoing research and gathering information (reading reports and academic literature, attending webinars, conducting key informant interviews, reviewing examples from other states, etc.) Compiling,

summarizing, and/or analyzing data. Compiling and summarizing pertinent research and current best practices related to the diagnosis, treatment, and prevention of rare diseases. Identifying and tracking relevant legislation.

#### Section 4 - Publicly Accessible Repository and Annual Reports

The council shall establish a centralized, publicly accessible repository of information. The department assumes it will create a website to provide best practices for health care providers on effective strategies for recognizing and treating rare diseases and provide resources for rare disease patients and their families seeking access to clinical care. It will contain information in a variety of languages for accessibility. Assumes department will seek existing materials from reputable sources and translate as needed.

#### Section Cost Estimates:

FY24 = 5.4 FTE and \$1,670,000

FY25 and ongoing = 5.0 FTE and \$1,484,000

0.2 FTE ongoing Public Health and Epidemiologist 3 will be the project manager. FTE Public Health and Epidemiologist 3 will be the project manager. This position will also oversee managing program budget, coordinating with contractor providing technical assistance.

2.0 FTE ongoing Health Services Consultant 3 will be responsible for working with the council and partners to establish and maintain the publicly accessible repository of information and draft the biennial report to the governor and the legislature. They will work with external and internal partners to compile a catalogue of rare disease research ongoing in Washington state that will be publicly accessible. One of the positions will also be responsible for performing the necessary organizing, tagging, cleaning, and updating necessary to keep the information repository current and an easy and effective interface for the public. They will support the council in the creation of accessible materials and coordinate public messaging campaigns and translations services.

Translation, Mailing, and Campaign Costs – FY24 \$572,000 and \$482,000 ongoing.

\$192,000 for 1,000-word documents to translate at the rate of \$0.24 per word. Estimating 20 documents will be produced in 40 languages per year.

Total mailing cost anticipated to be \$30,000. Assumes one mailing to all primary care and a select number of specialty care providers. This is a strategy used when we have critical information providers need to see, because it cuts through the clutter of standard email communication, they receive out of DOH. Estimate 75,000 selected primary care and specialty care providers at the rate of \$0.40 per mailing.

Total cost for Public Messaging Campaign anticipated to be \$350,000. This addresses the ask to “develop effective strategies to raise public awareness of rare diseases in the state.” Costs are broken out to \$40,000 for audience research; \$50,000 for development; \$10,000 for account management; and \$250,000 for implementation/placement of media. Research and development costs of \$90,000 drop in FY25 lowering outgoing year costs so only implementation of now existing material be used for campaign.

#### Personal Service Contracts - \$100,000 ongoing

Plan to contract with an organization that specializes in medical genetics/rare diseases for technical assistance, information gathering, and analysis. Meeting with partners and key informants to understand relevant issues. Conducting ongoing research and gathering information (reading reports and academic literature, attending webinars, conducting key informant interviews, reviewing examples from other states, etc.) Compiling, summarizing, and/or analyzing data. Compiling and summarizing pertinent research and current best practices related to the diagnosis, treatment, and prevention of rare diseases. Identifying and tracking relevant legislation.

#### Other Costs

Other costs include staff, and associated expenses (including goods and services, travel, intra-agency, and indirect charges).

Total cost for FY 2024 is \$2,798,000 and 10.8 FTE

Total cost for FY 2025 and ongoing is \$2,418,000 and 9.9 FTE

**Part III: Expenditure Detail**

**III. A - Operating Budget Expenditures**

Account	Account Title	Type	FY 2024	FY 2025	2023-25	2025-27	2027-29
001-1	General Fund	State	2,798,000	2,418,000	5,216,000	4,836,000	4,836,000
<b>Total \$</b>			2,798,000	2,418,000	5,216,000	4,836,000	4,836,000

**III. B - Expenditures by Object Or Purpose**

	FY 2024	FY 2025	2023-25	2025-27	2027-29
FTE Staff Years	10.8	9.9	10.4	9.9	9.9
A-Salaries and Wages	750,000	708,000	1,458,000	1,416,000	1,416,000
B-Employee Benefits	302,000	280,000	582,000	560,000	560,000
C-Professional Service Contracts	175,000	175,000	350,000	350,000	350,000
E-Goods and Other Services	1,503,000	1,210,000	2,713,000	2,419,000	2,420,000
G-Travel	4,000	4,000	8,000	8,000	8,000
J-Capital Outlays	23,000		23,000		
T-Intra-Agency Reimbursements	41,000	41,000	82,000	83,000	82,000
9-					
<b>Total \$</b>	2,798,000	2,418,000	5,216,000	4,836,000	4,836,000

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

Job Classification	Salary	FY 2024	FY 2025	2023-25	2025-27	2027-29
ADMINISTRATIVE ASST 3	50,592	0.1	0.1	0.1	0.1	0.1
BUDGET ANALYST 3	71,520	0.2	0.2	0.2	0.2	0.2
Fiscal Analyst 2	53,000	3.7	3.2	3.5	3.2	3.2
HEALTH SERVICES CONSULTAN 2	66,420	1.0	1.0	1.0	1.0	1.0
HEALTH SERVICES CONSULTAN 3	75,120	3.0	3.0	3.0	3.0	3.0
HEALTH SERVICES CONSULTAN 4	82,896	0.5	0.5	0.5	0.5	0.5
Health Svcs Conslt 1	53,000	1.6	1.3	1.5	1.3	1.3
PUBLIC HEALTH AND EPIDEMIOLOGIST 3	157,536	0.5	0.5	0.5	0.5	0.5
WMS02	114,360	0.2	0.1	0.2	0.1	0.1
<b>Total FTEs</b>		10.8	9.9	10.4	9.9	9.9

**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

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.