

ALASKA STATE LEGISLATURE

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Representative Dan Saddler

Serving Chugiak-Eagle River & Peters Creek

Sponsor Statement

House Concurrent Resolution 4, Version A

Proclaiming May 2025 as Myositis Awareness Month

Myositis is a rare autoimmune disease that causes a person's immune system to attack their muscles, resulting in chronic inflammation, weakness and pain. Myositis affects more than 50,000 Americans.

Myositis is often difficult to diagnose, causing treatment delays and diminished quality of life. Left untreated, some forms of myositis can be fatal.

While there is currently no cure, early detection, followed by appropriate and timely treatment, can put the disease into remission and improve quality of life for those with this disease.

House Concurrent Resolution 4 would raise Alaskans' awareness of this rare disease, by proclaiming May 2025 as "Myositis Awareness Month," and encouraging activities to build awareness.

Here in Alaska, HCR 4 could play a role in helping individuals recognize the symptoms of myositis and get treatment sooner. At the national level, it could also help promote further research into this rare disease, help doctors better understand its symptoms and treatment options, and bring hope to those affected.

HOUSE CONCURRENT RESOLUTION NO. 4

IN THE LEGISLATURE OF THE STATE OF ALASKA

THIRTY-FOURTH LEGISLATURE - FIRST SESSION

BY REPRESENTATIVE SADDLER

Introduced: 3/24/25

Referred: Health and Social Services

A RESOLUTION

1 **Proclaiming May 2025 as Myositis Awareness Month.**

2 **BE IT RESOLVED BY THE LEGISLATURE OF THE STATE OF ALASKA:**

3 **WHEREAS** nearly one in 10 Americans has a rare disease, and residents of the state
4 are among those affected by myositis and other rare diseases; and

5 **WHEREAS** idiopathic inflammatory myopathies, collectively referred to as myositis,
6 are rare, chronic, autoimmune muscle-wasting diseases, can cause debilitating muscle
7 inflammation, pain, fatigue, and trouble swallowing, and can result in myositis-associated
8 interstitial lung disease; and

9 **WHEREAS** more research is needed to identify the causes of myositis and modes of
10 treatments for the myositis group of diseases, including anti-melanoma differentiation-
11 associated gene 5 dermatomyositis, antisynthetase syndrome, dermatomyositis, juvenile
12 myositis, necrotizing autoimmune myopathy, inclusion body myositis, and polymyositis; and

13 **WHEREAS**, because myositis is difficult to diagnose, treatment is often delayed and
14 individuals who have myositis often experience difficulty finding a health care provider with
15 expertise in the disease; and

16 **WHEREAS** individuals who suffer from myositis experience a reduced quality of life

1 and a shortened life expectancy from complications related to myositis, especially those with
2 inclusion body myositis, and no cure has been found; and

3 **WHEREAS** The Myositis Association is the leading international patient advocacy
4 organization serving the myositis community, with a focus on patient services, education,
5 research, and public awareness to achieve a world without myositis; and

6 **WHEREAS** The Myositis Association is organizing a nationwide observance of
7 myositis awareness for the month of May 2025;

8 **BE IT RESOLVED** the Alaska State Legislature encourages residents of the state to
9 come together, learn about the symptoms and types of myositis, and support individuals and
10 families in local communities who are affected by myositis and can benefit from greater
11 awareness of these rare diseases; and be it

12 **FURTHER RESOLVED** that the Alaska State Legislature proclaims the month of
13 May 2025 as Myositis Awareness Month.

Fiscal Note

State of Alaska
2025 Legislative Session

Bill Version: HCR 4
 Fiscal Note Number: _____
 () Publish Date: _____

Identifier: HCR4-LEG-SESS-04-28-2025
 Title: MYOSITIS AWARENESS MONTH
 Sponsor: SADDLER
 Requester: (H) HEALTH AND SOCIAL SERVICES

Department:
 Appropriation:
 Allocation:
 OMB Component Number: 0

Expenditures/Revenues

Note: Amounts do not include inflation unless otherwise noted below. (Thousands of Dollars)

| | FY2026 | Included in | Out-Year Cost Estimates | | | | |
|-------------------------------|-------------------------|---------------------------|-------------------------|------------|------------|------------|------------|
| | Appropriation Requested | Governor's FY2026 Request | FY 2027 | FY 2028 | FY 2029 | FY 2030 | FY 2031 |
| OPERATING EXPENDITURES | FY 2026 | FY 2026 | | | | | |
| Personal Services | | | | | | | |
| Travel | | | | | | | |
| Services | | | | | | | |
| Commodities | | | | | | | |
| Capital Outlay | | | | | | | |
| Grants & Benefits | | | | | | | |
| Miscellaneous | | | | | | | |
| Total Operating | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |

Fund Source (Operating Only)

| | | | | | | | |
|--------------|------------|------------|------------|------------|------------|------------|------------|
| None | | | | | | | |
| Total | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |

Positions

| | | | | | | | |
|-----------|--|--|--|--|--|--|--|
| Full-time | | | | | | | |
| Part-time | | | | | | | |
| Temporary | | | | | | | |

Change in Revenues

| | | | | | | | |
|--------------|------------|------------|------------|------------|------------|------------|------------|
| None | | | | | | | |
| Total | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |

Estimated SUPPLEMENTAL (FY2025) cost: 0.0 *(separate supplemental appropriation required)*

Estimated CAPITAL (FY2026) cost: 0.0 *(separate capital appropriation required)*

Does the bill create or modify a new fund or account? No
(Supplemental/Capital/New Fund - discuss reasons and fund source(s) in analysis section)

ASSOCIATED REGULATIONS

Does the bill direct, or will the bill result in, regulation changes adopted by your agency? No
 If yes, by what date are the regulations to be adopted, amended or repealed?

Why this fiscal note differs from previous version/comments:

Not applicable, initial version. One page, zero note.

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|---|----------------------------------|
| Prepared By: <u>Sante Lesh, Deputy Executive Director</u> | Phone: <u>(907)465-4824</u> |
| Division: <u>Legislative Affairs Agency</u> | Date: <u>04/28/2025 02:47 PM</u> |
| Approved By: <u>Jessica Geary, Executive Director</u> | Date: <u>04/28/2025</u> |
| Agency: <u>Legislative Affairs Agency</u> | |