

ALASKA STATE LEGISLATURE
SENATE COMMUNITY AND REGIONAL AFFAIRS STANDING COMMITTEE

March 12, 2024

1:32 p.m.

MEMBERS PRESENT

Senator Forrest Dunbar, Chair
Senator Elvi Gray-Jackson
Senator Jesse Bjorkman
Senator Cathy Giessel

MEMBERS ABSENT

Senator Donald Olson, Vice Chair

COMMITTEE CALENDAR

SENATE BILL NO. 184

"An Act exempting the state from daylight saving time; and providing for an effective date."

- MOVED CSSB 184 (CRA) OUT OF COMMITTEE

SENATE BILL NO. 256

"An Act establishing May as Amyotrophic Lateral Sclerosis Awareness Month; and providing for an effective date."

- HEARD & HELD

SENATE BILL NO. 242

"An Act relating to assessment of property, boards of equalization, and certification of assessors; and providing for an effective date."

- REMOVED FROM AGENDA

PREVIOUS COMMITTEE ACTION

BILL: SB 184

SHORT TITLE: ELIMINATE DAYLIGHT SAVING TIME

SPONSOR(S): STATE AFFAIRS BY REQUEST

01/16/24	(S)	READ THE FIRST TIME - REFERRALS
01/16/24	(S)	CRA
03/05/24	(S)	CRA AT 1:30 PM BELTZ 105 (TSBldg)

03/05/24 (S) Heard & Held
03/05/24 (S) MINUTE(CRA)
03/12/24 (S) CRA AT 1:30 PM BELTZ 105 (TSBldg)

BILL: SB 256

SHORT TITLE: ESTABLISH ALS AWARENESS MONTH

SPONSOR(S): STATE AFFAIRS BY REQUEST

02/28/24 (S) READ THE FIRST TIME - REFERRALS
02/28/24 (S) CRA
03/12/24 (S) CRA AT 1:30 PM BELTZ 105 (TSBldg)

WITNESS REGISTER

GRIFFEN SUKKAEW, Staff
Senator Scott Kawasaki
Alaska State Legislature
Juneau, Alaska

POSITION STATEMENT: Presented the explanation of changes from version A to B on SB 184.

SENATOR SCOTT KAWASAKI, District P
Alaska State Legislature
Juneau, Alaska

POSITION STATEMENT: Offered closing remarks on SB 184.

SENATOR SCOTT KAWASAKI, District P
Alaska State Legislature
Juneau, Alaska

POSITION STATEMENT: Introduced SB 256 on behalf of the Senate State Affairs Standing Committee, sponsor by request.

JOE HAYES, Staff
Senator Scott Kawasaki
Alaska State Legislature
Juneau, Alaska

POSITION STATEMENT: Presented the sponsor statement and sectional analysis on SB 256.

BROOKE Lavender, President
Amyotrophic Lateral Sclerosis Awareness (ALS) Association
Girdwood, Alaska

POSITION STATEMENT: Gave invited testimony in support of SB 256.

MICHELE FOLEY, representing self
Fairbanks, Alaska

POSITION STATEMENT: Gave invited testimony in support of SB 256.

ACTION NARRATIVE

[1:32:34 PM](#)

CHAIR FORREST DUNBAR called the Senate Community and Regional Affairs Standing Committee meeting to order at 1:32 p.m. Present at the call to order were Senators Giessel, Gray-Jackson, Bjorkman, and Chair Dunbar.

SB 184-ELIMINATE DAYLIGHT SAVING TIME

[1:33:29 PM](#)

CHAIR DUNBAR announced the consideration of SENATE BILL NO. 184 "An Act exempting the state from daylight saving time; and providing for an effective date."

The intention is to adopt a Senate Community and Regional Affairs committee substitute (CS), take questions from committee members, and look to the will of the committee.

CHAIR DUNBAR solicited a motion.

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SENATOR GIESSEL moved to adopt the committee substitute (CS) for SB 184, work order 33-LS1037\B, as the working document.

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CHAIR DUNBAR objected for the purpose of discussion. He invited Senator Kawasaki to make closing remarks and Mr. Sukkaew to present the summary of changes.

[1:34:37 PM](#)

GRIFFEN SUKKAEW, Staff, Senator Scott Kawasaki, Alaska State Legislature, Juneau, Alaska, presented the explanation of changes from version A to B on SB 184.

[Original punctuation provided.]

Section 2: Changes the Effective Date from July 31, 2024 to November 4, 2024 in accordance with the Uniform Time Act of 1966.

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CHAIR DUNBAR removed his objection. Finding no further objection, CSSB 184 was adopted as the working document.

[1:35:40 PM](#)

SENATOR SCOTT KAWASAKI, District P, Alaska State Legislature, Juneau, Alaska, made closing remarks on SB 184, emphasizing that the decision to adopt Daylight Savings Time is complex due to its varied impact on individuals. He highlighted health and economic concerns tied to the change and noted that Alaska's vast size and latitude cause significant differences in sunset times, affecting businesses. He expressed gratitude to the committee for considering SB 184.

[1:36:52 PM](#)

SENATOR BJORKMAN stated that the Alaska State Association of Bankers opposes SB 184 due to concerns about its impact on their ability to conduct business. He explained that the opposition stems from the need to operate during critical business hours aligned with the East Coast.

[1:37:36 PM](#)

SENATOR GIESSEL stated she has prior experience with the issue at hand and predicts opposition from the chambers. She noted that similar opposition prevented a prior bill from passing that was introduced by former Senator Anna McKinnon. She opined that in an electronic age, economic activities, including stock exchanges and international transactions, can be conducted smoothly online.

[1:38:22 PM](#)

SENATOR GRAY-JACKSON recalled agreeing with an audience member during the last hearing about favoring Standard Time over Daylight Savings Time. However, she stated she is now happy to see Daylight Savings Time move forward.

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CHAIR DUNBAR stated that since a debate on the floor may not occur, he supports the points raised by Senator Bjorkman in the last hearing about the impact of moving away from Daylight Savings Time on after-work recreation. He noted he would likely have supported a bill for permanent Daylight Savings Time. He said it is the biannual time change that he finds most disruptive to health and constituents. He clarified that staying on permanent Daylight Savings Time is not legally possible, making this the only option to end the time changes. He urged moving SB 184 forward.

CHAIR DUNBAR solicited the will of the committee.

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SENATOR GIESSEL moved to report CSSB 184, work order 33-LS1037\B, from committee with individual recommendations and attached zero fiscal note(s).

[1:40:05 PM](#)

CHAIR DUNBAR found no objection and CSSB 184(CRA) was reported from the Senate Community and Regional Affairs Standing Committee.

[1:40:09 PM](#)

At ease.

SB 256-ESTABLISH ALS AWARENESS MONTH

[1:41:51 PM](#)

CHAIR DUNBAR reconvened the meeting and announced the consideration of SENATE BILL NO. 256 "An Act establishing May as Amyotrophic Lateral Sclerosis Awareness Month; and providing for an effective date."

He said the committee will hear an introduction, sectional analysis, and invited and public testimony on SB 256.

[1:42:19 PM](#)

SENATOR SCOTT KAWASAKI, District P, Alaska State Legislature, Juneau, Alaska, introduced SB 256 on behalf of the Senate State Affairs Standing Committee, sponsor by request. He stated that May is nationally recognized as ALS Awareness Month (Amyotrophic Lateral Sclerosis Awareness Month). He explained that SB 256 aims to increase awareness in Alaska by proclaiming May as ALS Awareness Month in the state.

[1:43:11 PM](#)

JOE HAYES, Staff, Senator Scott Kawasaki, Alaska State Legislature, Juneau, Alaska, paraphrased the sponsor statement for Sb 256:

[Original punctuation provided.]

The month of May is recognized as National ALS Awareness Month. ALS is also known as Amyotrophic Lateral Sclerosis or Lou Gehrig's disease. ALS was first identified in 1869. In the 155 years since, there is still no effective treatment and no cure.

ALS is a neurodegenerative disease that affects the nerve cells in the brain and spinal cord that control

voluntary muscle movement and breathing. ALS is a 100% fatal disease. There is no cure for ALS.

ALS is a rare disease, affecting approximately 5 in 100,000 people. Approximately 30,000 people in the United States are currently living with ALS and approximately 60 people in Alaska are currently living with ALS. 90 percent of patients diagnosed with ALS have no family history or disease. Only 10 percent of patients have familial/hereditary ALS.

ALS may strike at any age, but most people who have ALS are between 40 - 70. There are currently only 3 medications that slow the progression of ALS, and one medication that targets familial ALS specifically. These medications only extend life expectancy by a few months.

ALS causes the motor neurons in the central nervous system to degenerate over time and die. This affects a person's ability to talk, walk, and breathe. People with ALS will eventually lose their ability to speak, become paralyzed, and lose the ability to breathe on their own. ALS patients die from respiratory failure.

The mean survival for someone diagnosed with ALS is two to five years. Every 90 minutes someone is diagnosed with ALS, and every 90 minutes someone dies from it. Veterans are 1 1/2 to 2 time more likely than non-service members to be diagnosed with ALS. There is no single test to diagnose ALS, it is diagnosed only after numerous other conditions have been ruled out (a delayed diagnosis results in delayed treatment/start on medications). It can take a patient over a year to get an ALS diagnosis.

ALS symptoms vary. In limb onset ALS, it may manifest as weakness in a patient's hand or foot, arm or leg. In bulbar onset ALS, it may manifest as trouble speaking or swallowing. There currently is no known cause of ALS. 100 percent of ALS patients are unaware of the cause of their disease.

[1:46:21 PM](#)

MR. HAYES presented the sectional analysis for SB 256:

[Original punctuation provided.]

Section 1. Amends AS 44.12 to add a new section to Article 2 to read: Sec. 44.12.190 Amyotrophic Lateral Awareness Month.

Section 2. Creates an immediate effective date under AS 01.10.070(c).

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CHAIR DUNBAR announced invited testimony on SB 256.

1:47:15 PM

BROOKE LAVENDER, President, Amyotrophic Lateral Sclerosis Awareness (ALS) Association, Girdwood, Alaska, gave invited testimony in support of SB 256. She described ALS as a fatal disease that progressively weakens muscles, leads to paralysis, and ultimately causes respiratory failure. She stated there is no current cure and total disease duration costs are about \$1.4 million. She shared a personal connection, noting her cousin Nick Sloan, a US Marine sergeant, passed away from ALS and had founded a nonprofit called Attack Life Sloan in Texas. She emphasized that veterans are twice as likely to be diagnosed with ALS and described her dedication to raising awareness and supporting those affected in Alaska, where approximately 60 people currently live with ALS. She highlighted the lack of a multidisciplinary ALS clinic in Alaska, forcing patients to travel or relocate for essential care, adding significant emotional and financial strain. She stressed that SB 256 would help raise awareness and advocate for comprehensive ALS care services in the state. She urged support for the bill, stating it honors those lost to ALS, offers hope to those currently battling the disease, and advocates for better access to care.

1:50:35 PM

MICHELE FOLEY, representing self, Fairbanks, Alaska, provided the following testimony in support of SB 256:

[Original punctuation provided.]

Thank you for allowing me the opportunity to testify today.

My name is Michele Foley, and I would like to share my support for Senate Bill 256. I was officially diagnosed with ALS in April 2023. My journey to a diagnosis took almost a year. When I went to my doctor with my first symptoms, she initially diagnosed me

with a vitamin deficiency, then as my symptoms became more pronounced, she thought I perhaps have a compressed nerve in my neck.

1:51:14 PM

MS. FOLEY continued:

Eight months after first showing symptoms, I was referred to a neurologist in Anchorage, who thought I might have ALS. It took another two months and a trip out of state to receive an official diagnosis, and another two months after that to jump through all the hoops to get insurance approval to begin on the first of only three medications available to ALS patients that has been shown to slightly slow ALS progression. Prior to my diagnosis, I had no idea what ALS was. I was completely blindsided by my diagnosis.

When you are given an ALS diagnosis, you are told that the life expectancy is two-five years. But living with ALS, I have realized that you don't just die. In those two to five years, ALS will take away everything I value and hold dear. These two to five years will be filled with the gradual loss of the use of my hands, arms, feet, legs- the ability to talk, walk and breathe. One slowly (or for some, quickly) loses the ability to do everyday tasks. Grasping door handles to open doors becomes impossible. One doesn't have the strength to zip up a zipper, or the dexterity to button a shirt. Doing basic tasks leaves me breathless. I will eventually completely lose my ability to talk, instead relying on a digitized voice to communicate for me. Anyone who knows me knows that I love to talk! I will lose the ability to walk, and eventually, move at all. At some point in the disease progression, ALS patients require full time care, for everything from bathing, toileting, turning over in bed, to someone to clean out their feeding tube and trach tube, and getting into and out of a wheelchair. It is an ugly, cruel disease.

As someone who knew nothing about ALS, and was diagnosed with it, it is important to me to raise awareness about this fatal disease. Increased awareness would help patients and doctors be more aware of the symptoms of ALS, leading to an earlier diagnosis. It can take anywhere from one to three

years to receive a diagnosis. Raising awareness is also important to bring understanding to the need for additional research and funding for research to develop meaningful treatment for ALS, and perhaps soon, a cure. There are currently only three FDA approved medications that slow the progression of ALS, and these only extend life expectancy, at most, a few months. Finally, increasing people's knowledge about ALS, what the disease is and how it affects a person, may bring awareness to the challenges and battles that an ALS patient faces, and create a better understanding for those fighting this brutal disease.

On a personal note, this summer our family decided to visit family in the UK while I could still walk and talk (though much more slowly). We rented a canal boat in Wales. My 17-year-old grandson was the captain for the four days and got us through the canal locks and drawbridges expertly. We moored the boat one day and my daughter and I went down the hill to a quaint little store. On the way back up the hill I asked for her arm to help me up the hill. I said, "ALS has made me old before my time." We both started crying. Back at the boat the captain asked what was wrong and I told him that I was sad because of ALS. He started crying. As we were holding onto each other, my middle granddaughter saw us and asked why we were crying. We told her why, and she hugged us and said she was sorry. The youngest grandchild, 13, asked what was going on and I told her I hated having ALS. She responded, looking at her non-existent watch "Okay but don't we need to get going?" And that's what we're doing. We go forward in hope, and love and sometimes tears, but always in hope.

I appreciate you allowing me the chance to voice my support for Senate Bill 256.

[1:55:47 PM](#)

CHAIR DUNBAR opened public testimony on SB 256; finding none, he closed public testimony.

CHAIR DUNBAR shared a personal connection to ALS through a soldier he served with in the Army National Guard who was also a Marine and deployed to Iraq and Afghanistan. He noted the soldier was diagnosed with ALS after being assigned out of state and recalled visiting him and his family during a training. He

expressed surprise that veterans are 1.5 to 2 times more likely to develop ALS, suggesting this points to potential causes and hope for a cure. He emphasized the personal impact ALS has on friends and family and thanked the bill sponsor and Ms. Foley for her moving testimony.

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CHAIR DUNBAR held SB 256 in committee.

[1:58:09 PM](#)

There being no further business to come before the committee, Chair Dunbar adjourned the Senate Community and Regional Affairs Standing Committee meeting at 1:58 p.m.