



THE STATE
of **ALASKA**
GOVERNOR BILL WALKER

Department of
Health and Social Services

ALASKA COMMISSION ON AGING

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February 28, 2017

Representative Jason Grenn
Alaska State Capitol, Room 418
Juneau, AK 99801-1182

Subject: Support for HB 43, New Drugs for the Terminally Ill

Dear Representative Grenn:

The Alaska Commission on Aging (ACoA) is pleased to offer our support for HB 43, a bill authored by you and co-sponsored by Representatives Scott Kawasaki, Les Gara, and Harriet Drummond, that would allow terminally ill patients who have exhausted other available treatments the "right to try" investigational treatments after consultation with their doctors and to provide immunity to their prescribing physicians, manufacturers and distributors of new treatments that have not yet received federal approval.

End of life care is particularly important to older Alaskans and their families. In addition to the potential lifesaving measures that experimental drugs may offer, new treatments can also reduce the pain, discomfort, and inflammation that often accompany terminal illnesses and provide another option to use instead of narcotic drugs. Although the Food and Drug Administration has a process called "compassionate use" that provides patients with terminal illness access to unapproved treatments still in clinical trials, we understand that this process is onerous and can take considerable time to pursue, which is a luxury that a person at the end of life simply cannot afford.

Decisions regarding medical care are personal and belong to patients in consultation with their doctors. If a patient is willing to try a new treatment and understands the risk, and the doctor believes that the treatment may help the patient more than anything else that is available, then the patient with limited and precious time should have the final say in their treatment. Further, patients also have the right to know that these treatments are costly and typically not covered by private insurance and public funding. Ultimately, payment for an investigational treatment will depend on the agreement reached by the patient, his/her doctor, and the drug manufacturer. To this end, we recommend language to be included in the bill that would require medical practitioners to counsel their patients about costs and payment responsibility for unapproved treatments in order to promote transparency and reduce disappointment.

The Commission supports HB 43 and appreciates your leadership of this legislation. We believe that HB 43 will provide hope to Alaskans who suffer from a terminal illness by offering access to investigative treatment options and creating new research pathways to save lives. Please feel free to include the Commission's letter in the bill packet for HB 43.

Sincerely,

Handwritten signature of David A. Blacketer in blue ink.

David A. Blacketer
Chair, Alaska Commission on Aging

Sincerely,

Handwritten signature of Denise Daniello in blue ink.

Denise Daniello
ACoA Executive Director

Cc: Representative Scott Kawasaki
Representative Les Gara

Representative Harriet Drummond