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Sent: Monday, February 27, 2017 2:12 PM

Subject: Written Testimony in support of HB43 New Drugs for the Terminally Ill

Representatives Drummond, Gara, Grenn, and Kawasaki (Sponsors of HB43):

I write to you today in support of HB43 with the short title "New Drugs for the Terminally Ill". I understand that your time is limited and therefore I will effort to be as brief as possible. In June of 2011, my father was diagnosed with Amyotrophic Lateral Sclerosis (ALS), sometimes known as "Lou Gehrig's Disease". For those unfamiliar, this disease slowly saps a person's ability to move, rendering them bedridden. Eventually, it takes away their ability to breathe, at which point, they die. It should be noted that the disease does not affect a person's mind. Therefore, they are acutely aware of their daily deterioration and because of this, the mind becomes a prisoner within the body. For my father, the deterioration began in June with a reduced range of movement in his left leg. At this point he had been working 12-hour days 5-6 days per week as a machinist. I feel this is important to point out because of the extended hours and physical nature of the job. He was by all accounts a very strong and healthy man at the time of diagnosis. By late fall, he had completely lost the ability to walk. At Thanksgiving, he held our then 5-month old son for the last time as his arms had become too weak for him to trust with such precious cargo. When he finally lost all movement in his limbs, he would "hug" our children by nuzzling his face against them.

As we entered the depths of winter, he and I carried on what conversations we could, trying to accelerate what should have been many more years of passing knowledge and wisdom from Father to son. These conversations became increasing difficult as the disease made his breathing quite labored, even with the assistance of a [bipap machine](#). While the painful and emotional moments are too many to list, the most painful came when I asked him the simple question, "Dad, are you angry?" He responded with uncommon grace and humility by uttering one word with every labored breath. "I'm. Not. Angry. I'm. Just. Sad. That. I. Won't. See. Your. Kids. Grow. Up." In the early morning hours of February 1, 2012, he died at the all-too-young [age of 58](#).

My father was a good man and my hero. He was a tireless worker, a great role model, and an unparalleled family man. He took a chance on Alaska in 1996 when he moved his family from the only home it had ever known to a place where we had no connections, no network, no family, and no friends. The gamble paid off for all of us. He saw the potential in this place. He fought like we all do to make a life here. In the end, I wish the State had afforded him the right to fight his disease with the same ferocity. Recently, in the Washington Post, there [was an article](#) detailing the experience of a man who has for all intents and purposes beaten ALS through advanced therapies pioneered by doctors at the Emory ALS Center in Atlanta, Georgia. In reading about this man, I became aware of the "Right To Try" movement. Soon thereafter I became aware of the bill which I write to you in support of today. I implore you to pass this bill and to encourage your colleagues in the Senate to do the same. I cannot say for sure that these advanced therapies would have saved my father's life, but they may yet save someone's father or mother, daughter or son.

Thank you all for your consideration of this important legislation. If you have any questions, feel free to contact me via this email address or at the information below.

Jason Norris
12026 Tidepool Place
Anchorage, Alaska
99515

CC: House Speaker Rep. Edgmon, House Majority Leader Rep. Tuck, House Minority Leader Rep. Millett, Rep. Kopp (House District 24), and Sen. Von Imhof (Senate District L)



Eugene Huang, M.D.

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Juneau, AK 99801

Phone: 907.586.5762

3/1/2017

To Whom It May Concern,

I am writing this letter in support for House Bill 43, "New Drugs for the Terminally Ill." I believe that this bill will help provide terminally ill patients greater access to the new drugs that may potentially make a significant difference in their lives.

Sometimes in our practice, a patient may be in a situation where they have exhausted all available options, yet have not given up hope and want to try additional measures that may help them. Every other week, even just within my limited scope of cancer practice, there are new drugs being developed and tested in early-phase clinical trials. The pace of biotechnology research and drug development has significantly accelerated in just the last few years, offering patients more options and hope for treatment.

I believe that House Bill 43 will help bring new scientific discoveries closer to patients whom need them, within the appropriate context and safeguards.

Sincerely,

A handwritten signature in blue ink, appearing to read "E. Huang", is written over a light blue horizontal line.

Eugene H. Huang, MD
Medical Director
Southeast Radiation Oncology Center



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