

FEDERAL LAW ENFORCEMENT OFFICERS ASSOCIATION

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September 22, 2016

The Honorable Ron Johnson, Chairman
The Honorable Thomas Carper, Ranking Member
Committee on Homeland Security & Governmental Affairs
United States Senate
Washington, DC, 20510

Dear Mr. Chairman and Ranking Member Carper:

I am pleased to submit this statement on behalf of the membership of the Federal Law Enforcement Officers Association (FLEOA) for today's hearing, entitled "Exploring a Right to Try for Terminally Ill Patients." FLEOA is a non-partisan, non-profit professional organization representing more than 26,000 federal law enforcement officers from 65 agencies. This hearing will allow for a broader conversation about the rights of terminally ill Americans and their ability to access treatment options. We also understand and support the Chairman's legislation, S. 2912, the "Trickett Wendler Right to Try Act," which will extend a right to Americans who currently have none and give them an option to "fight" their illness. We respectfully request that this statement be made a part of the hearing record.

The ranks of the FLEOA Membership are not unlike the rest of America. We have many proud Members who have served on the front lines of protecting our nation and then were unexpectedly sidelined from that "battle" by the diagnosis of a "so called" terminal disease. Those diseases range from rare cancers, to ALS to other debilitating genetic diseases where current treatment options are limited but future treatments promising.

Unfortunately, the current FDA protocols for accessing these treatments are mired in a bureaucratic process that is complicated, burdensome and lengthy. Additionally, the current FDA "Expanded Access" or "Compassionate Use" programs have both been cited by various GAO and Congressional reports as limiting and lacking compassion. What we see in both programs is a "passing the buck" between the FDA and pharmaceutical companies and a lack of a patient's ability to have a say or a "right" to access promising treatment options. In both programs, the FDA and pharmaceutical companies retain a veto authority over a patient - regardless of the merits of the patient's request.

This effectively eliminates any patient's "rights" and is the antithesis of what our nation stands for.

As a case in point, FLEOA recently contacted Misubishi-Tanabe pharmaceuticals of Japan. Mitsubishi has a drug called edavarone which has been successfully used overseas for a few years as a stroke treatment and last year as a treatment for ALS patients, which have a

two to seven year life expectancy. The drug has been widely heralded as a success and a few months back, Mitsubishi made an FDA application to have the drug approved in the United States. Presently, that approval won't occur until the summer of 2017. Additionally, FLEOA requested if they would entertain a compassionate use of expanded access requests – the company replied no. How can a company with a treatment that has been used and documented as successful, be given close to a year approval process and unwilling or unable to provide the drug via the established FDA programs? How is that compassionate or American?

As the myriad of reports have indicated, the FDA trial pipeline is blocked and stymied by a bureaucracy entrenched in antiquated policies vs advocacy for expediting health care options. Instead of making access to this trial pipeline easier and less burdensome for Americans and giving them a right to access it, it remains with 1950's protocols. Even the FDA's fleeting attempt to streamline the Compassionate Use or Expanded Access application – is wholly ineffective if both the FDA and drug corporations retain a right to say no.

Terminally ill Americans don't have the time or energy to fight extraneous battles – other than the one occurring in their bodies. As a compassionate nation, we should be breaking down hurdles for our fellow citizens battling terminal illnesses – not making them higher. Extending a “right to try” to these American's is a step in removing hurdles and adding some compassion back into health care.

FLEOA appreciates your Committee's time and effort examining this American issue and hopes your Committee and the Congress addresses it with the same urgency terminally ill American's use while searching for a helpful treatment or a cure.

Respectfully,

Nathan Catura
Nathan Catura
FLEOA President