

USN LCDR (Ret.) Matthew Bellina testimony: 10/3/2017

Ladies and Gentlemen, thank you for inviting me to speak here today. I also want to extend a heartfelt “thank you” to my representative, Congressman Brian Fitzpatrick. He has been a tireless advocate for not only the ALS Community but for all terminally ill Americans.

In all of my advocacy work the question I am asked most often is “How could anybody oppose the Right To Try Bill?”. While I appreciate the sentiment, I respect the fact that there are well-meaning people with ideological differences. I would like to illustrate their arguments and why I feel they are based on false logic.

The argument I hear most often is that we already have an Expanded Access Program in the FDA that approves over 99% of applications. On average, this is less than 2,000 applications per year. By conservative estimates there are nearly 30 million Americans living with incurable conditions. I would like to draw an analogy here. Imagine there were 30 million Americans eligible for food stamps. 2,000 people applied and were approved. The other 29,998,000 Americans never completed an application and starved to death. Would we be patting ourselves on the back for a successful program? I should hope not. The major difference here is that food stamp reform would involve a sizeable fiscal note and the Right To Try Bill does not. The FDA's involvement in the Compassionate Use of Medicine has an unintended chilling effect on the pharmaceutical industries willingness to operate outside of the boundaries of the clinical trial system. This obstacle can and should be removed.

The other argument I hear often is that the State Right To Try Bills have had little impact, so why should we pursue a Federal bill? The 100 or so cancer patients in Texas would have a very different opinion about the overall impact, but for arguments sake let's assume that number is not significant enough to make a federal effort. If anybody can point me to a case in the last 50 years where the courts have sided with State over Federal law on matters of Interstate Commerce, I would concede that there is no value added to passing this bill. As it is, no respectable pharmaceutical company would jeopardize their ability to participate in Interstate Commerce for the sole purpose of providing their drug in a single state. This bill is needed to protect the pharmaceutical industry from litigation and allow them to respect the individual state laws. Once this bill is passed we should see more widespread use of the 37 state laws. I have no illusion that this will solve the entire problem but it is absolutely a step in the right direction and a step we need to take now.

I am sympathetic to the position of Mr. Kenneth Mochs and other pharmaceutical executives. Often times the greater good is to put the trial over the rights of the individuals. This however is not a one-size-fits-all situation. The processes for all trials and drugs are unique and must be treated that way. Pharmaceutical executives make enough money that they need to have the courage to explain these decisions to the patients and families and not hide behind a government agency to make these ethical decisions easier for them.

I know that it is probably too late for me and I have made my peace with that. I need to know before I die that if my children find themselves in this unenviable position, that this nation that I proudly served will respect their liberties and their right to make their own decisions about their medical treatments. Thank you for having me here. God Bless you and God Bless this great nation of ours.