

Committee Testimony on Senate Bill 991  
Executive Director, Reason Institute  
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Good afternoon Mr./Madam Chairman and members of the committee. My name is Paul Krepps, and I am the executive director of the Reason Institute. Thank you for providing me an opportunity to advocate today on behalf of Senate Bill 991. I would especially like to thank the bill's sponsor, Sen. Pappageorge, for recognizing an important issue for the people of Michigan and acting on their behalf through this legislation.

Senate Bill 991 represents what is commonly known as "Right to Try" legislation. The Right to Try legislative movement was born roughly two years ago in response to the suffering experienced by thousands of terminally ill patients throughout our nation. A diagnosis of terminal illness itself is heartbreaking. Even more heartbreaking, however, is the understanding in many cases that there are experimental treatments that could alter the patient's prospects, but are inaccessible because the drugs in question have not yet made it through the U.S. Food and Drug Administration's approval process. The Right to Try is just that – giving terminally ill patients the right to try experimental drugs which have the potential to improve and/or extend their lives.

I think most of us would agree that the FDA serves an important purpose of ensuring that the medications prescribed to us are safe and effective. Yet the reality is that the FDA's drug approval process is a long and winding road. With so many researchers spending thousands of hours and companies spending billions of dollars to develop new drugs, it is not surprising that the FDA acts as an unintentional bottleneck, significantly lengthening the time it takes for promising new treatments to reach patients. As this process unfolds, patients who could benefit from the drugs are left waiting. In the case of terminally ill patients, the wait inevitably results in individuals dying without the benefit of even trying medical treatments that may have altered their lives for the better. The time for experimental drugs to reach final approval is too long, and for many the results come too late. In other words: without the ability to try, the only choice is to die.

Imagine being told that you have an aggressive disease for which there is no approved treatment plan, and in six to eight months you will likely be dead. There are no options given in that message. And because there are no options, there is no hope. What do people do when they have no hope? In the case of sick people, for better or worse they often turn to Google. Imagine that after your diagnosis you search the Internet, and in doing so learn that a major pharmaceutical company has created a new drug that is meant to address the very disease that is killing you. You excitedly meet with your doctor and ask if she will get this drug and administer it to you. "Well, in reviewing your case I also came across that," she says. "But I didn't mention it to you because at this point it's considered an experimental drug – it hasn't even been given FDA approval for clinical trials."

For terminally ill patients, that is painful to hear. "There's a medication out there that could help me. Perhaps instead of dying in six months, I could survive twelve months and live to see my son graduate from high school. But I can't have that medication."

The position our organization has taken in this discussion is based on the inalienable rights of life and liberty enshrined in the Declaration of Independence. While the length of a man's days is ultimately in the hands of his Creator (Ps. 139:16), God has blessed us with the wisdom and creativity of scientists and medical researchers who every day are discovering new ways to treat illnesses, extending both the length and quality of life for individuals afflicted with medical conditions of all types. We believe that every person facing a terminal illness should have the freedom to decide whether or not to receive an experimental drug that may be helpful, as well as the freedom to assume the risk that is inherently associated with that decision.

Opponents of this legislation have historically raised objections related to the liability pharmaceutical companies or health care providers might face in instances where an experimental treatment has negative results for the patient. We recognize this as a legitimate concern, and are thankful to see that Senate Bill 991 very clearly addresses this point.

If this bill is approved and signed into law, Michigan will join three other states that have given their citizens the promise that, if affected by a terminal illness, they will have the ability to choose experimental but potentially life-changing medications. Or, to put it simply, you will be offering them hope at a time in their lives when it is needed the most.

I encourage you to support Senate Bill 991. Thank you for your thoughtful consideration of this important legislation.