



Trump Signs Law Letting Terminally Ill Patients Try Experimental Drugs

Michael Tennant

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President Trump on Wednesday signed into law legislation that gives terminally ill patients the right to try experimental treatments that have not yet been approved by the Food and Drug Administration (FDA).

The Trickett Wendler, Frank Mongiello, Jordan McLinn, and Matthew Bellina Right to Try Act, named for patients who could benefit from the legislation (Wendler has since passed away), allows those with terminal illnesses to seek treatments that have passed the FDA's initial clinical trials but have not completed the rest of the agency's lengthy approval process.

“With the Right to Try law I'm signing today, patients with life-threatening illnesses will finally have access to experimental treatments that could improve or even cure their conditions,” Trump said at the signing ceremony. “These are experimental treatments and products that have shown great promise, and we weren't able to use them before. Now we can use them.”

Trump gave the bill, which had passed only the Senate last year, a boost by promoting it in his 2018 State of the Union address.

The law is based on similar legislation that has already been passed in 40 states, according to the Arizona-based Goldwater Institute, which has been at the forefront of the right-to-try effort. “Today, we have given new hope to Americans struggling with a terminal illness,” said Goldwater Institute president and CEO Victor Riches. “Federal law now protects the right of dying patients to obtain and use cutting-edge medicines without asking first for government permission.”

Appearing at the signing ceremony — and getting a hug from Trump — was eight-year-old Jordan McLinn, who suffers from Duchenne muscular dystrophy, a degenerative genetic disease that usually results in death by young adulthood. Jordan attended the 2015 ceremony at which then-Governor Mike Pence signed Indiana's Right to Try bill into law, and he was brought to the House of Representatives during debate over the federal bill. Jordan has been accepted into a clinical trial for a drug that seems to be slowing the progression of his disease, but his mother, Laura McLinn, said she continued promoting right-to-try “for terminally ill patients who aren't in that ‘lucky three percent’ of the patient population who make it into trials.”

The law has its critics, of course. The Hill reports that “most Democrats and public health groups oppose” it because they believe that letting patients, rather than the FDA, decide what’s best for them “could put patients in danger.”

Other critics simply believe the law is oversold.

Besides the fact that most states already have similar laws on the books, the FDA already has a process to enable patients to try experimental drugs and has, in recent years, approved 99 percent of all applications.

Moreover, even though the law allows patients to request experimental drugs, it does not require drug companies to supply them. Companies may be reluctant to do so for a variety of reasons. First, it can be a very expensive proposition, and insurance companies usually don’t pay for unapproved treatments, so only those who can afford to pay for their own drugs are likely to get them. Second, should an experimental treatment cause harm to a patient, its manufacturer might be sued. Third, adverse consequences could delay or even prevent FDA approval of a drug.

The law’s supporters argue that the administrative burden of the FDA’s current process discourages patients from pursuing it. They also believe there are sufficient safeguards in the act to allay fears of lawsuits and FDA delays, though these haven’t been tested in court, and the law’s requirement that adverse effects be reported to the FDA is hardly encouraging to pharmaceutical makers. Indeed, as *Reason*’s Mike Riggs observed, the “incentives are aligned for pretty much everyone except the drug companies.”

In other words, it’s a wait-and-see proposition. For now, the momentum is in favor of right-to-try. Whether drug companies will get on the bandwagon remains to be seen. If they do and the adverse effects of drugs accessed under the law begin to accumulate, “the pendulum will swing back to the current political equilibrium,” averred the Cato Institute’s Michael Cannon.

Still, any movement in the direction of liberty is welcome. Trump deserves credit for getting this freedom-oriented legislation onto the books.