Is “Right to Try” Really “Right to Pay?”

The law could create opportunities for hucksters and snake-oil salesmen to prey on those who are vulnerable.

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More than 1.7 million Americans will be diagnosed with cancer this year. Almost one in three of them will eventually succumb to it. Knowing these odds, patients are eager to try anything to improve on them. People with cancer and their loved ones want quicker access to the latest medicines—even if they are still at an experimental stage.

That’s why so many Americans applauded passage of the Right To Try Law, which President Trump signed in May. The measure creates a legal pathway for people with terminal illness to access new medications that have only been through one phase of Food and Drug Administration (FDA) approval.

While well intentioned, the law could create opportunities for hucksters and snake-oil salesmen to prey on those who are vulnerable. As the FDA develops its protocols for right to try, the agency must ensure that patients are protected from anyone trying to game the system.

Consider the case of BrainStorm Cell Therapeutics, a drug company with a new experimental stem cell treatment called NurOwn. The treatment is for amyotrophic lateral sclerosis, the terrifying disease that killed baseball superstar Lou Gehrig. Those suffering from the neurogenerative disorder gradually but inexorably lose all ability to control muscle movements. Eventually, patients are completely isolated in their immobile bodies—typically until their breathing stops.

NurOwn is harvested from the stem cells of each individual patient. It’s currently under development, and results to date have been inconclusive. A midstage study involving 48 participants found those given the drug did appear to respond, though for most the benefit didn’t last.

It’s highly uncertain whether NurOwn will eventually pass the FDA’s scientifically rigorous safety and efficacy standards. Nevertheless, NurOwn’s developer sought to make it available to patients. But here’s the catch: “Right to try” doesn’t mean “right to try for free.” And that’s where BrainStorm Cell Therapeutics had its own brainstorm: Proposing to sell its experimental treatment for hundreds of thousands of dollars.

Insurance doesn’t generally cover treatments that have not been approved by regulators or proven to work in clinical trials. That means patients would have to pay for the therapies out of

their own pocket. Some could be desperate enough to sell their house to come up with the money.

Right-to-try legislation isn't designed for commercial profit. Yet after Trump signed the bill, requests for NurOwn skyrocketed and BrainStorm's shares closed up 2.8%.

BrainStorm ultimately bailed out on offering NurOwn under the right-to-try law, but only after a maelstrom of controversy. Yet the company's initial impulse was likely only the first of many potentially unsafe and exploitative actions, which the FDA must act to prevent.

No one actually knows if NurOwn works. But desperately ill patients may gamble everything to try it anyway. Such are the unintended consequences of right-to-try.

No wonder the American Society of Clinical Oncology opposes right-to-try legislation on both the state and federal levels.

"ASCO supports access to investigational drugs outside of clinical trials, when adequate patient protections are in place," ASCO chief medical officer Richard Schilsky, MD, said. "We don't support right-to-try legislation, however, because these laws ignore key patient protections without actually improving patient access to investigational drugs outside of clinical trials."

Let's hope BrainStorm—and other likeminded companies—have learned that cashing in on the uncertain hopes of desperate patients is an unacceptable industry practice. And let's make sure the FDA sends that message in no uncertain terms.

Peter J. Pitts, a former FDA associate commissioner, is president of the Center for Medicine in the Pubic Interest.

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