The 'right to try' in Illinois

Bipartisan measure improves terminally ill patients' access to experimental drugs; new laws already in place in some states

by Illinois Sen. Michael Connelly (senatorconnelly21@gmail.com)

It's not very often in the rough-and-tumble history of Illinois politics that you find an issue that unites all spectrums of the political divide — until now.

I'm from a region in the western suburbs of Chicago that is traditionally Republican — DuPage County.

My ally in this endeavor is state Rep. Greg Harris, who represents a district in the city of Chicago that one would describe as a bastion of liberal Democrats.

Rep. Harris and I are united in trying to provide Illinoisans facing terminal illness with expedited access to experimental medications that may save or prolong their lives. This joint legislative effort hopes to bring what is referred to as the Right to Try Act to Illinois.

What drew my attention to this legislation from the outset is the fact that elected officials from both sides of the political spectrum saw this issue the same way. Any piece of legislation that liberal Colorado Gov. John Hickenlooper and conservative Louisiana Gov. Bobby Jindal see the same way deserves a hard look.

Hit movie has real-life resonance

Late last year, my wife and I were at home watching the 2013 film "Dallas Buyers Club," which was set in 1985. The film's main character is the hard-living cowboy Ron Woodroof.

Woodroof contracts AIDS, and doctors give him 30 days to live. During the initial HIV/AIDS scare of the mid-1980s, very little was known about the disease.

In real life, Woodroof spent seven years fighting for the right to access alternative medicines and treatments already available in other countries. While it makes for a dramatic movie, scenes like these — of people who are terminally ill and denied access to experimental medical treatments — play out across the Midwest every day.

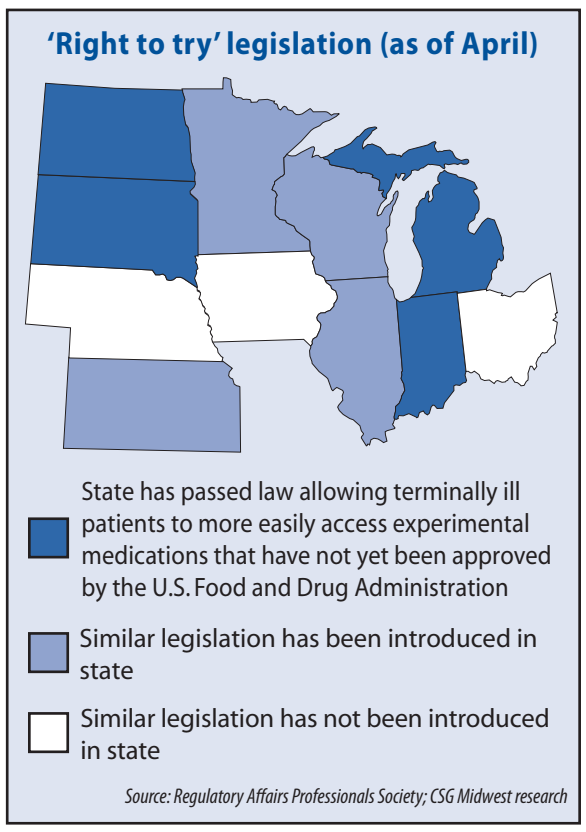
There are few, if any, of us who have not had a relative, friend or colleague afflicted with cancer, Alzheimer's, AIDS or some other terminal illness. Last year, much of our country was caught up in the frenzy of the ALS Ice Bucket Challenge, which not only raised awareness and tens of millions of dollars toward research to find a cure for Lou Gehrig's disease, but also began a national dialogue on access for terminally ill patients to potentially life-saving medications.

Today, these people have few options. One can attempt to enroll in a clinical trial, but it's estimated that 97 percent of terminally ill Americans are not in a clinical trial. Sadly, many of those 97 percent travel to foreign countries to gain access to the newest medications.

Currently, the U.S. Food and Drug Administration has what is called the "compassionate use" program. Each year, roughly 1,000 Americans successfully complete the program's application process.

Critics of the program say it is complicated, time-consuming and expensive. To begin the application process, patients need a doctor willing to spend approximately 100 hours on it. Clearly, 100 hours spent writing an application for an experimental process for one patient may not be the most efficient use of time for an oncologist treating scores of other terminally ill patients.

Next, the manufacturer of the medication must also submit lengthy documentation. The FDA then has a month to review the submission and either grant or deny the request.



A separate committee called the Institutional Review Board must also approve the patient's use of the medication. This process can take a month to complete. Terminally ill patients who receive a diagnosis of less than six months to live have little time to waste.

To be sure, the FDA has announced plans to shorten the application process, which is helpful but only addresses one part of the approval process. If your child is dying from a terminal illness and you and your physician are aware of an investigational medication that appears to be helping other children, shortening an approval process doesn't necessarily accomplish the objective of expedited access to that medication.

I am hopeful that the FDA will implement an expedited process soon. What a sea change that would be for the terminally ill.

In the meantime, states are stepping up to provide a framework for their residents to access these very same medications. The Arizona-based Goldwater Institute has taken a lead role in promoting "right to try" legislation. Kurt Altman, Goldwater's national policy adviser and general counsel, has testified before more than 20 state legislative bodies just this year alone.

"'Right to try' allows terminally ill patients access to medicines that have passed Phase 1 of the FDA approval process but are not yet on pharmacy shelves," Altman says. "This expands access to potentially lifesaving treatments years before patients would normally be able to access them."

Based on the institute's model legislation, the Illinois Right to Try Act (HB 1335 and SB 29) would allow a patient access to experimental medications if:

- the patient has a terminal illness and has exhausted all conventional treatment options;
- the patient's doctor has advised the use of the investigational medication;
- the drug has successfully completed basic safety testing and is part of the FDA's ongoing approval process;
- the patient has provided "informed consent" acknowledging the potential risk of the drug; and
- the company developing the medication is willing to make it available to the patient.

It's important to note that the act does not obligate drug manufacturers to provide an experimental drug to a patient nor obligate insurers to provide coverage to an eligible patient who seeks experimental treatment.

Bill has broad statewide support

Rep. Harris and I have met with representatives from a number of pharmaceutical companies, the Illinois State Medical Society, members of the legal community and other interested constituencies across the state to discuss the details of the bill. I am not aware of any opposition to the legislation.

In Illinois, there is strong bipartisan and bicameral support for the act; as of mid-April, HB 1335 had passed the House by a vote of 114-1-1 and SB 29 had passed the Senate by a vote of 52-0.

If the act becomes law, Illinois will join a growing number of other states with right-to-try laws, including Indiana, Michigan, North Dakota and South Dakota in the Midwest.

Upon the filing of our respective bills, Rep. Harris aptly noted: "I hope this shows that in Illinois, Republicans and Democrats, social liberals or social conservatives, can reach across the aisle to solve problems for suffering families. ... 'Right to try' is a huge leap forward to help connect our state's most terminal patients with some of the nation's best medical resources, including those here in Chicago, and give them the gift of life."

I am hopeful that Illinois will join the many other states that are providing their residents access to new medications that provide them a chance to fight to live.

I would like to personally thank the Goldwater Institute and my legislative colleague Greg Harris for their advocacy on this sensitive issue. Additionally, I would like to thank the two dozen legislative allies who have signed on as co-sponsors of this important legislation.

Sen. Michael Connelly, a Republican from Wheaton, was first elected to the Illinois Senate in 2012 after serving two terms as a state representative.

Submissions welcome

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