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 (senatorconnelly241@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 sets this legislation apart 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 treatment but also began a national dialogue on access for terminally ill patients to potentially life-saving medications.

In 2010, former U.S. Rep. Cannon introduced a bipartisan 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

This page is designed to be a forum for legislators and constitutional officers. The opinions expressed on this page do not reflect those of The Council of State Governments or the Midwestern Legislative Conference. Responses to any FirstPerson article are welcome, as are pieces written on other topics. For more information, contact Tim Anderson at 630.925.1922 or tanderson@csg.org.