

Battling cancer, former lawmaker advocates for 'Right to Try' measure

By: Gary Grado September 29, 2014



Former Arizona lawmaker Laura Knaperek receives chemotherapy for cancer. (Photo by Gary Grado/Arizona Capitol Times)

It's been 28 days since her last infusion of powerful chemicals to fight her cancer and Laura Knaperek settles in for another one.

The former lawmaker is cheerful, sitting upright in a recliner as a machine clicking like a metronome pumps a mixture of substances through dangling tubes into her body at the University of Arizona Cancer Center at St. Joseph's Hospital. Even though Knaperek, 59, is in the second round of chemotherapy since she was diagnosed with ovarian cancer in October 2012, she's not letting up on her political consulting tasks, one of which is leading one of two campaigns to pass Proposition 303.

The measure, known as Right to Try, allows drug makers and people who are terminally ill to bypass the federal government to use unproven drugs. The argument for it is that the U.S. Food and Drug Administration takes too long to approve drugs, many of which are already on the market in Europe, effectively driving up their cost while people die. Although there is no organized opposition to the proposal, opponents have argued that using unproven drugs can be harmful to patients, provide false hope, leave doctors with liability under federal law and spur the U.S. government to sue Arizona.

Knaperek said it is an issue of personal liberty.

"The alternative is you do nothing and you die, or you do some strange treatment, you go to Mexico and do baking soda through an IV, or Laetrile, or medical marijuana, hemp oil or there's enzyme treatment. There's all kinds of things and they cost thousands and thousands of dollars," Knaperek said. She said she hasn't experienced the frustration of being denied an experimental drug, but she knows people who have the

mindset of doing whatever it takes to survive, especially if their children are dying.

Knaperek, a Tempe Republican who served from 1995 to 2006 in the Arizona House, said she thinks she would be involved in the Right to Try campaign even if she hadn't been stricken with cancer, but not to the level she is now. Ovarian cancer is frequently fatal, mostly because its difficulty to detect allows it to spread before discovery.

Cancer took her mother at 41 years of age, and Knaperek's 25-year-old son was also diagnosed with a form of the disease at the same hour across the country on the day she found out. She said her son has struggled, and he's getting better.

"I'm not doing this for me, this isn't about me, it's about everybody, but one day it might be me, I don't know," she said.

The Goldwater Institute, a conservative think tank that advocates for libertarian causes in the Legislature and uses the courts to fight its idea of government over-reach and defend its causes, pushed the legislation to put the proposition on the ballot.

Goldwater also has an organized political campaign to pass it. Gibson McKay, a spokesman for the Goldwater campaign, said an April poll of 1,293 likely voters found 82 percent approved of the measure.

Knaperek said she isn't in it just to win an election.

She said her campaign, Right 2 Try in Support of Proposition 303, will continue after the election if voters pass it. The committee will serve as a springboard for creating a stakeholders' advisory committee on implementing the law and a nonprofit to serve as an information center and advocacy center.

The proposal allows terminally ill patients to use drugs that have been through the first phase of clinical testing, but not granted FDA approval. The agency has a Compassionate Use program, which allows some terminally ill patients to use drugs outside of a drug maker's clinical testing.

The FDA has not formally opposed the measure, but has made some public statements that the legislation erodes its authority and congressional mandate.

Joan Koerber-Walker, president and CEO of the Arizona Bio-Industry Association, has essentially been the lone voice opposed to the measure, debating McKay on television and writing about it in a blog.

She said she isn't against giving people the freedom to try, but it is morally wrong to tell them they can try without giving them a proper way to do it.

Koerber-Walker said the FDA already has an established avenue, and the measure puts nothing in place to help people who are going to take advantage of the new law.

"If this passes there will have to be some kind of entity, whether it is an independent nonprofit, or the state health department, somewhere, someone is going to have to deal with all of the patients that say, 'OK, now help me try,'" Koerber-Walker said.

Knaperek said the ballot proposal has no mandates for doctors, insurance companies or pharmaceutical companies, so there are many questions about how the process will work for patients.

She said under the proposal a doctor would have to be willing to sign a prescription and then the patient would have to go to a drug company, which would either sell it or give it for free.

One of the concerns of opponents is there will be unscrupulous drug makers and doctors who will take advantage of patients financially and harm them physically, which is one of the issues the committee would tackle.

Knaperek said there will have to be a process and structure set up through legislation to support the constitutional provision and address problems that arise.

"We know there are going to be problems," she said.

She also wants Arizona to be a model for implementing the process for the rest of the country.

Goldwater has plans to try to pass legislation in eight to 12 states next year and has already succeeded in Colorado, Louisiana and Missouri.

"People who have a terminally ill disease have to live in the moment, they have to live in the day, they also have to know there's something to live for and there's something to help them to achieve that," Knaperek said.