Why Patients Need the Right to Try

Dr. Jim Neely - State Representative -Missouri's 8th District

Mr. Chairman, members of the committee, my name is Jim Neely. I'm a physician and State Representative from Cameron, Missouri. I'm here to go on the record in support of this bill because terminally-ill patients don't have time to wait for the FDA to approve investigational treatments.

I've been practicing medicine for over 30 years. Over that time, I've seen patients with medical conditions and issues of life that have been very challenging to deal with; from cancer to multiple sclerosis.

I remember treating my first AIDs patient back in 1985 in Florida. After the examination, I walked out of the room with very little idea of how to help him. I regrouped with other physicians, and we agreed, without access to an experimental treatment, he was *completely* hopeless.

There were clinical trials at the time, but he wasn't eligible. We needed more options. The FDA didn't approve the first effective antiretroviral for AIDs until the following year. It was too late.

Disincentives for Compassionate Use

Throughout my medical career, I've been troubled by the laws that restrict suffering patients' access to investigational treatments. As a physician, my practice is guided by evidence, so I understand the importance of our clinical trial system; however, terminally-ill patients deserve the option to try investigational treatments after they have exhausted all approved treatment options and are no longer eligible for clinical trials,

As I began considering this issue as a State legislator, my daughter Kristina was diagnosed with Stage 4 colon cancer. She had four children at the time, and was carrying her fifth, which severely limited her eligibility for clinical trials. From a research perspective, I understand the importance of studying a uniform group of patients, but there has to be room for compassion for patients, like my daughter.

Before she passed away, Kristina was adamant that her right to try treatments "shouldn't be up to somebody that has no involvement in my care." I believe this bill goes a long way toward giving more options to terminally-ill patients and their doctors.

Restricted Access Harms Indigent Patients

A friend of mine, Ross Nichols, came to testify in support of the Right to Try bill we passed in Missouri. At the time, he was receiving treatment at MD Anderson for glioblastoma, the most common and aggressive form of brain cancer. Ross knew that the experimental treatments he received were unlikely to save to his life, but he still sought to enroll in clinical trials, explaining, "my number one job right now is being a dad, and I'll do whatever I can do to try to extend that."

Ross told the committee that he was testifying for the bill because he wanted people in Missouri to have access to the same treatments that were available to him at the research institutions he could afford to travel to. He was right.

Many people fighting for their life, cannot afford to spend what-could-be their final months traveling across the country in order to receive investigational treatments. I'm glad Ross was able to travel to receive treatment that gave him hope, but he shouldn't have had to. Ross passed away in February of 2015. I'm glad his hope for other patients lives on with this bill.

Restricted Access Strains the Doctor-Patient Relationship

Rick Suozzi, father of the late Kim Suozzi, also came to testify in support of our right to try bill in Missouri. His daughter was diagnosed with glioblastoma at age 21, during her final semester at Truman State University. Kim knew her diagnosis was a death sentence, but she went to extraordinary lengths for a small chance to survive. She traveled to the top cancer research institutions - Dana Farber, UCLA, MD Anderson, and Duke- just to participate in clinical trials that gave her a glimmer of hope.

Kim enrolled in three trials in the last six months of her life. When she was no longer eligible for clinical trials, she lied to research doctors about her treatment history in order to make herself eligible. Can any of us blame her?

Thank you for giving me the opportunity to share these stories. I believe government should create opportunities for people to care for each other, not erect and maintain barriers. This bill knocks down some of the major barriers to care that make life even more difficult for terminally-ill patients. With that, I’d be happy to take any questions.